# your rights, your voice, your life

# Down but not out

Disabled women speak

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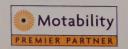
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#### **EDITORIAL**

Editor Ian Macrae ian.macrae@disabilitynow.org.uk

Deputy Editor John Pring Tel: 020 7619 7326;

john.pring@disabilitynow.org.uk

News Editor Katharine Quarmby Tel: 020 7619 7324;

katharine.guarmby@disabilitynow.org.uk

**Design/Production Editor Jamie Trounce** 

**Sub-Editor Stephen Games** 

Reporters Paul Carter Tel: 020 7619 7325:

paul.carter@disabilitynow.org.uk

Sunil Peck Tel: 020 7619 7321; sunil.peck@disabilitynow.org.uk

Cathy Reay Tel: 020 7619 7261; cathy.reay@disabilitynow.org.uk

**Editorial Assistant Kelly Mullan** 

#### **ADVERTISING**

**Advertising Manager Patrick Durham-Matthews** 

Tel: 020 7619 7336;

patrick.durhammatthews@disabilitynow.org.uk

Advertising Executive Emma Roskell

Tel: 020 7619 7320; emma.roskell@disabilitynow.org.uk

Advertising and Marketing Assistant Suzan Hillman

Tel: 020 7619 7120; suzan.hillman@disabilitynow.org.uk

#### **ADDRESS**

Disability Now, 6 Market Road, London N7 9PW

Editorial: 020 7619 7323; fax: 020 7619 7331;

textphone: 020 7619 7332; email: editor@disabilitynow.org.uk

#### SUBSCRIPTIONS

FREEPOST RLZU-YJSG-ACBJ, Disability Now, 800 Guillat Avenue, Kent Science Park, Sittingbourne ME9 8GU Tel: 0845 120 7001 or email dnsubs@servicehelpline.co.uk

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### editorial

### A matter of rights and death

This month's question to ponder: with which group in society, other than disabled people, would anyone be allowed to get away with suggesting that the solution to problems they encounter would be to kill them? Answer: none. Would anyone stand up in public and say that anyone who lived outside the tenets of the Christian or

**66** Any responsible and influential member of society should be arguing for an equal right to proper and appropriate treatment 🦠

any other faith existed in such a state of misery and spiritual poverty that the only hope for them was to be released by having their life ended? No. Thankfully, that kind of thinking hasn't been considered to have currency for centuries. There may well be people who believe that homosexuality is such an aberration that death is the only way of dealing with it. But let them try standing up and saying so in public

and they'd be loudly and rightly howled down.

So why is it OK for such pronouncements to be made about disabled people? The contention that the best way of dealing with people with dementia is to end their lives, for example, puts their status and value on a level with that of a seriously-injured horse or terminally-ill pet dog. What any responsible and influential member of society should be arguing for is an equal right to proper and appropriate treatment.

But what is almost more outrageous than the pronouncements of Baroness Warnock and others in the fields of medicine and ethics who have gone before her more outrageous even than such people believing that they have the right to recommend ending someone else's life - is that, by and large, society challenges neither what they say nor their self-given right to say it. The views of those who do oppose and challenge such opinions are lost in the general murmur of at worst agreement and at best complacency.

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### your rights, your voice, your life





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### newsview

### **Axed McGuire praised by allies**



#### **Sunil Peck**

When Anne McGuire took over as minister for disabled people, she said she wanted to be judged on what she did and how she did it.

Three years on, following the news that she has lost her job in Gordon Brown's ministerial reshuffle. disabled activists speak of her with an affection and respect at odds with the usual reaction to ministers.

"She was a smashing minister who did a lot for disabled people," says Sir Bert Massie, former chair of the Disability Rights Commission (DRC). "She understood the disability movement and the importance of human rights and independent living.

"She took through the Life Chances report and sought to help protect the DRC's work when the

**Equality and Human Rights** Commission was being established. She had to work within the constraints of any other minister but she really understood the agenda."

Fellow activist Rachel Hurst, director of Disability Awareness in Action, calls McGuire's move "tragic". "She really understood the idea that disabled people should have their own voice. She really wanted to take forward the [UN] convention and she was making every effort to do so."

McGuire (pictured above, centre, with Disability Now editor Ian Macrae at our relaunch party last year) was also the first minister for disabled people to be a disabled person herself (she has diabetes).

But it was the combination of McGuire's personality and passion for disability rights that

impressed Julie Newman, chair of the UK's Disabled People's Council. "I respected her and felt she respected me. She worked hard to listen to us. She set up meetings and consulted actively. It wasn't a paper exercise; she interacted with us and took seriously what we considered to be our major issues."

### 66 She really understood the idea that disabled people should have their own voice >>

Nick Danagher, a disability equality consultant and former co-chair and executive director of the National Centre for Independent Living, also talks fondly of the rapport that McGuire established with disabled people. "She was always visible and

available to talk to people. She listened to what people had to say," he says.

Danagher says that because McGuire attended user-led events, like NCIL's AGM and events staged by local disabled people's groups, she won people's trust. "It was obvious that she was genuinely working hard while being up against some difficult barriers in government to put our agenda on the table."

The disabled Labour MP Anne Begg says McGuire "will be missed". "I'm really sad that Anne has gone because I thought that she was doing a great job. She has survived two reshuffles and it's a shame that she's no longer there."

McGuire told Disability Now that she has been "overwhelmed" by the kind messages she has received from disabled people and says that her time as minister for disabled people was the most rewarding of her 11vear ministerial career.

As for her legacy, she points to the signing of the UN Convention, the government's independent living strategy, and a wider recognition that disabled people should be "judged on what they can do and not for what they can not."

And she says she hopes she contributed to "maintaining the momentum towards equality for disabled people".

### breakingnews

# Hard times ahead as recession looms

**Sunil Peck** 

Campaigners are warning that the "credit crunch" is already affecting a significant number of disabled people and their families.

The disabled childrens' charity, Newlife, reports a 400 per cent increase in the number of requests for assistance in August from parents wishing to purchase specialist equipment. It says that some parents are using credit cards to pay for wheelchairs after failing to obtain statutory funding.

Sheila Brown, chief executive of Newlife, said: "There are a quarter of a million children across the country desperate for essential equipment.
Statutory services often spend a pitiful amount on equipment for each disabled child and some charities are now unable to offer any support or have waiting lists of up to two years."

Trudi Beswick, the chief executive of Caudwell Children, a charity for terminally-ill and disabled children, such as Tilly Griffiths (pictured), reported similar problems. She said:



"We've seen a massive rise in families requiring help. June, July and August are usually our slowest months but, because people obviously couldn't [afford to] go away they were our busiest this year. Already the needs of families that come to us have doubled since last year.

"Families that didn't originally fit our criteria are coming back after someone

in the family has been made redundant or lost their job, needing our help."

Disabled people's organisations are also bracing themselves for the recession. Barbara Litchfield, chief executive of Enfield Disability Action, said she expected that the increase in energy prices would lead to more people seeking financial and debt advice. Claire Glasman, from

WinVisible, said: "People are saying it's really hard to afford home care and a lot of people in our network have dropped out of using home care. We're heavily involved in supporting and helping people who have been cut off or forced to [stop using home care]. The need for help and support is greater than ever. We're very worried about people's welfare when they aren't getting the basic services they need."

While the big disability charities RNIB and Leonard Cheshire Disability said that they did not expect to feel the effects of falling incomes for some time, Scope has already had to make several high level managers redundant as part of a strategy to save two-and-a-half million pounds.

The Trades Union Congress has already predicted that unemployment will hit two million next year. Peter Purton, the TUC's disability policy officer, fears that disabled people will be hit as the credit crisis deepens. He said: "In many organisations, if there's any perception that anyone has high support needs or might be considered less productive, especially in the commercial sectors, then they're obviously going to be at risk of being first in the firing line. Even though it might be illegal to act in that way,

there's not going to be very much people can do to challenge it in reality unless they have a union to fight the case."

Paul Wright, a debt and disability case worker employed by Sheffield Citizens Advice Bureau, said: "There are a lot of disabled people who are having difficulty paying fuel bills, and more and more people tend to be going for bankruptcy." He added: "We are anticipating that there is going to be an increase in people with a disability who are in debt because of the economic downturn. If you're on a lower income or disability benefit, then you're going to have more problems as prices in the shops and fuel prices go up."

Paul Treloar, of Disability Alliance, questioned the thinking behind the government's decision to press ahead with plans to shift more disabled people off incapacity benefit and into work.

"If there are fewer jobs then there's going to be more competition for places. It is true to some degree that we need to up-skill disabled people, but that does undermine the case for more conditionality [setting conditions for receiving benefits] in making people do job searches because it's going to be difficult enough anyway."

Remploy has closed 29 factories since last November, But its spokeswoman said that it was too early to know how the credit crisis would affect its remaining factories.

Sue Bott, director of the National Centre for Independent Living, fears that disabled people will suffer as local authorities seek to save money to compensate for funds tied up in Icelandic bank accounts.

"My fear is that the shortfall will be made up from cutbacks in services and increases in charges, even though charges are already sky-high. I fear that they are going to pick on that section of the community that finds it most difficult to get across their point of view and that's people using social care services."

Disability arts, too, could suffer. Tony Heaton, the chief executive of Shape, said: "There is no doubt that the impending recession will have an impact on our sector as much of our fundraising is generated from trusts that rely on returns from investment and the banking and finance sector. There is also the potential for our services to suffer, particularly training. This is an easier budget to cut than many when times get hard."

· Additional reporting by Cathy Reay



### Survivors' Thalidomide protest

Scores of Thalidomide survivors from across the globe demonstrated outside the German Embassy last month to protest against pharmaceutical giant Chemie Grunenthal. Nick Dobrik, joint chairman of the International Contergan Thalidomide Alliance (ICTA), said: "The German government has colluded with this reprehensible company to systematically deny Thalidomide sufferers basic human and civil rights, dignity and the right to a self determined life." Protestors say that Chemie Grunenthal has left almost 3,000 German survivors without adequate financial support. The embassy refused to comment or meet protestors. John Roberts (pictured), a campaigner from Brighton, said: "I think it is outrageous that nobody from the embassy will even speak to us when so many people have travelled so far to be here."

### newsroundup

Rail system fails passengers



One in three disabled travellers is left stranded because rail companies fail to provide vital assistance. according to a new report.

"Mystery shopper" surveys by the national rail watchdog Passenger Focus found that staff at stations were often not ready to help passengers who had booked assistance through the Assisted Passenger

Reservation Service (APRS).

In 15 per cent of cases, there were no provisions to help the disabled passenger get off the train.

The research was carried out in London and the south-east in 2007 and in Scotland. Wales and the rest of England in spring 2008.

A spokeswoman for the Disabled Persons Transport Advisory Committee said: "APRS needs a comprehensive review. The system is failing many disabled people. Ironically, a failure can cost the rail operator a great deal of money by delaying train departures."

An Association of Train **Operating Companies** spokesman said that it and train operators have been trying to improve APRS and there was "evidence that these efforts are paying off".

### Credit crisis hits disability charity

The disability charity Scope announced a series of high-level redundancies in response to the financial crisis affecting the UK economy.

Five senior managers, including two executive directors, were made redundant and more job losses are likely to follow.

The "credit crunch" has caused a shortfall of £1.5 million a year.

Scope chair Alice Maynard said: "Our commitment to disabled people's equality and human rights remains at the heart of our mission."

### **Pentagon hacker** fights extradition

Gary McKinnon, the British computer expert who hacked into the Pentagon and NASA systems in the United States, faces the prospect of extradition to the USA despite being diagnosed with

Asperger's syndrome.

Experts said the condition may have affected his actions during the alleged offences and his behaviour after his arrest.

Mr McKinnon faces a series of charges dating back ten years.

He is alleged to have hacked into around 100 military computer systems, causing several hundred thousand pounds' worth of damage.

He faces up to 60 years in jail, although his sentence is likely to be shorter.

He lost an appeal against extradition in the European Court of Human Rights.

Mr McKinnon's lawyer, Karen Todner, said she was making representations to the home secretary, Jacqui Smith. She said she would argue that her client should be prosecuted here on medical grounds.

She told Disability Now: "It has become apparent that Gary's disability contributed [to his alleged offences]. I'm sure it contributed to his reaction on being caught. He pleaded quilty on all charges without even having a solicitor present."

A Home Office spokesman said the home secretary had received representations from Mr McKinnon's lawyers and the Home Office would respond in due course.

### **Equality panel has no** disabled members

A panel set up to study inequality in Britain does not have a single disabled member, its chair admitted.

The National Equality Panel of nine academic experts has been asked to provide the government with an authoritative analysis of inequality in Britain by the end of 2009.

Its findings will help the government "address persisting equality gaps".

Strong criticism was voiced by Sir Bert Massie, who chaired the Disability Rights Commission.

He said: "Disability is an issue that can potentially affect everyone in the country: we could all become disabled. It is important to have a disabled person on this panel."

The Employers' Forum on Disability also called for the day-to-day experience of disabled people and employers to be represented in the panel's work.

A spokeswoman for the Cabinet Office said: "While the panel was not set up to be representative of particular backgrounds or perspectives, one of the panel members in particular has strongly focused her work on disability issues, and will provide expertise in this area."

### Disabled children miss out on fun

Disabled children miss out on choices and activities that non-disabled children enjoy, a new report reveals.

The Going Places! report, published by campaigning group Every Disabled Child Matters, found that disabled children often couldn't go out with friends away from their parents. The Department for Children, Schools and Families was unable to comment on the report.

### Children still held in adult wards

Under-16s are still being treated in adult psychiatric wards, in spite of a government pledge in 2006 to stamp out the practice.

The Conservative Party highlighted new statistics showing that up to 750 children under 18 may have been treated in adult mental health wards in 2007-8, even though ministers committed to eradicate this figure by November 2008.

In 2007-8, 26 children under the age of 16 and almost 400 under the age of 18 were treated in the adult mental health trusts that took part in the survey.

Professor Peter Beresford, a mental health service-user and activist, added: "There is already evidence of a lack of security and safety in adult

### Fatwa opens door to dog



A blind Muslim student became the first person allowed to take his guide dog into a British mosque.

Mahomed-Abraar Khatri, from Leicester, was granted a fatwa by the Muslim Law (Shariah) Council UK, enabling him to enter his local mosque with his guide dog, Vargo.

Dogs are not usually allowed in mosques because Muslims believe their purpose is to hunt and quard and they are seen as "unclean". But after Mr Khatri asked for the ban to be lifted at the Bilal Mosque, it was softened to exclude guide dogs, regarded as "working" animals.

Pervez Hussein, a blind Muslim guide dog-owner from Herefordshire, told Disability Now: "There are so few Muslim quide doq-owners that I don't feel this will shift barriers; though if ever this happens again, there is this great example to fall back on."

Pictured above is Mr Khatri with the mosque's head imam, Hafiz Rehman

services, so the idea of kids in this...environment is seriously worrying."

A Department of Health spokesman said it would be

"commissioning extra provision where required" and was "confident" the trusts would meet its promise on time.









### campaigns

### Justice system 'failing' on hate crime

The government's chief prosecutor has admitted that the justice system's performance on hate crime is 'catastrophically low'. Katharine Quarmby reports



he outgoing director of public prosecutions and head of the Crown Prosecution Service (CPS), Sir Ken Macdonald QC (pictured, above), has given a ground-breaking speech about how the criminal justice system treats disability hate crimes - and dubbed it a "catastrophically low level of performance".

In his speech last month to the Bar Council and the

**Equality and Diversity** Forum, which jointly hosted the event, Sir Ken described the dearth of disability hate prosecutions as "a scar on the conscience of criminal justice. All institutions involved in criminal justice, including my own, share the responsibility."

Sir Ken said that too many disabled people were living in fear because the criminal justice system was letting them down and urged

police and prosecutors to make sure that hate crimes were prosecuted as such.

He said he believed that disability hate crime was "very widespread" and added: "Where there is evidence of hostility, police and prosecutors must ensure that it is put before the court. It is our duty to give effect to the law which supports the struggle for disabled people to live as full and valued members of society."

He added that "a mistaken focus on vulnerability risks enhancing an already negative image of disabled people as inherently weak, easy targets and dependent. This approach is wrong. It means that the opportunity to condemn the prejudice and hostility of the offender is missed."

He promised action to improve the way the CPS handled disability hate crime prosecutions. Lead hate crime prosecutors from all CPS areas would combine to enhance awareness and build competence and there would be assessments of case handling performance.

Sir Ken praised the work of Disability Now (among other organisations) in highlighting the issue and quoted directly from

Getting Away with Murder. the report we co-published with Scope and the UK's Disabled People's Council.

Disabled people present welcomed Sir Ken's intervention but warned that more must be done.

Ruth Bashall, the co-chair of the Metropolitan Police Service's disability independent advisory group, said progress within the police service towards understanding what disability hate crime was remained very slow. She wanted more involvement in training from disabled people's organisations – for which they should be paid.

This point was echoed by Andrew Lee, from People First, who was frustrated by the "lack of skills" shown by many law officers in the criminal justice system in investigating and prosecuting disability hate crime. He later added that the system needed a "kick up the arse" to improve its performance.

Sir Ken concluded by thanking disabled people's organisations, including Disability Now, for their campaign work and stated that it was "not tenable to have a criminal justice system that does not protect disabled people".

### politics

With a new minister for disabled people, and Labour regrouping around their beleaguered Prime Minister, Disability Now was at the party conferences last month to hear what the Conservatives and Liberal Democrats would do for disabled people

### "I'm on a learning curve"

It's back to square one for the Liberal Democrats, with their latest disability shadow nine months into his new role

ohn Barrett MP, the Liberal Democrats' latest spokesperson on disability, appointed just after Nick Clegg became leader nine months ago, is still settling into his new role.

As their third disability spokesman in as many years, he has a hard slog ahead in familiarising himself with the issues, engaging with the disability movement and pushing for real change.

"I'm on a strict learning curve," he says, "and I'll be the first to admit that I've got a lot to learn - but the determination is there."

Indeed, Barrett is worryingly short on policies, and his knowledge of key concepts, such as the social model of disability, is threadbare.

This lack of focus on disability was apparent at the conference in general, with no mention of access issues and no disabled people called to speak during a debate on the party's rail expansion programme.

There were some positive



moves, with the launch of a group aimed at achieving diversity in the party, and the renewal of a pledge to extend winter fuel payments to severely disabled people, while shadow work and pensions secretary Jenny Willott MP said rates of disability living allowance were "nowhere near sufficient" to cover the costs of living for disabled families.

As for Barrett, though, he can point to efforts he made three years ago in his constituency, Edinburgh West, to help families with disabled children. He arranged for information packs that simplify applying for benefits, parking badges and other services. "I approached Anne McGuire about this," he says. "I told her that people faced a real battle in accessing information and knowing what to do. She said the government is doing all it can, but I don't think there is joined-up thinking."

He says discrimination against disabled people is still rife, although he has vet to formulate detailed solutions. "There has got to be a change in mindset so that it would be equally outrageous to discriminate against disabled people as it would be to discriminate against other groups," he says. "I don't think

legislation on its own can do it. There are huge problems in the workplace. Employers must be involved in a way they haven't been before."

Working towards equality for disabled people is something everyone can agree on, he says. "We've entered a unique phase in that the other two party leaders both have disabled children. There is political common ground. Now it's just a matter of resources. If we're facing a recession. there will probably be more of a limitation there. Providing healthcare, respite care, educational provision – they're all expensive – and I think that's the battle ahead."

So what makes Liberal Democrats different from the Tories and Labour? "The Conservatives see it as a question of how to get more people into the marketplace. The Labour government has let a lot of people down over the years and I'd like to think that the Liberal Democrats would work with individuals and organisations to improve the system. Hopefully, we're not facing an immediate election, and we have time to develop good policies between now and then."



### Agreeing to disagree

Conservative disability shadow Mark Harper's disagreements with the government seem to be over delivery rather than policy, says Paul Carter

ven the confident and self-assured Mark Harper cannot disguise the fact that he and his party are broadly in agreement with government plans to move more disabled people back into work.

Having said that, much of the talk by his shadow ministerial colleagues during the Conservative party conference took a harder line than had previously been heard on reforming the welfare system.

But Harper (pictured left, during a visit to the charity Aspire's national training centre) insists that the stronger language is aimed at those on benefits such as jobseeker's allowance, and

not disabled people who are unable to work.

"Obviously, those people will be treated with respect and dignity, and won't be forced onto work programmes," he told us.

"There is a bigger group of people who actually want to work, and who could work. but are unable to do so at the moment, and need more care and support to do so."

Theresa May, shadow leader of the House, also told the conference there must be a "revolution in the workplace" to introduce the flexible working that would enable disabled people to work.

There are other areas of government policy with which Harper is in broad

agreement, such as individual budgets, but he says he has doubts about the speed of delivery.

"The government have previously said that there are 1.7m people who would be eligible for individual budgets, but there are only 7,000 people currently getting them.

"They've said that they want all people who are eligible to have the choice of having them by 2010, but given that that is two vears away...it seems unlikely that will happen."

Pressed on how a Conservative government would ally the desire to get people into work against an increasing backdrop of inadequate social care

provision, he says individual budgets are the best way to allow people to tailor care packages to make working easier.

"People need control over the timing and delivery of that care to fit around work. Individual budgets can give people more choice and control. If we don't do that, then those people won't be able to work."

With a new minister for disabled people having taken office in last month's reshuffle, Harper also expresses concern that the position might become marginalised in government, with the new minister Jonathan Shaw also holding responsibility as minister for the south-east.

As for ratifying the UN Convention, Harper says Conservatives agree with the government that there should be two opt-outs: the uniformed armed forces and education.

"There is a concern that the convention could be used to take away the choice to send a child to special school, if they think that's right for their child."

The party also pledged to introduce combined personal budgets for people with health and social care needs, with a means-tested element for social care needs, and a free healthcare element.

### mediawatch

### No Amnesty on dodgy gags

With fat mothers-in-law, thick Irish, chiselling Jews and Asians with quirky English rightly and thankfully consigned to history as subjects for comedy, it seems disabled people are the last group standing as targets for dubious gags.

For the latest example. don't think of the usual suspects - Jim Davidson, the late Bernard Manning we're talking here about The Secret Policeman's Ball, a high-profile televised charity gig at the Royal Albert Hall. Hosted by Amnesty International and broadcast by that protector



of the public service remit, Channel 4.

Opening the show, Frank Skinner made much of the fact that he's now over 50. In that case, he really ought to know better. Interesting that in targeting Muslim cleric and persona non grata in Britain Abu Hamza, he chose to major not on his faith, but on his prosthetic hands. Jokes about him being a Muslim are unacceptable if they rely on Skinner exploiting a stereotype created by non-Muslims. So why is the fact that the guy has prosthetic hands considered as fair game?

Sean Lock targeted people with wheat intolerance which to them may have seemed rum enough - but described them as behaving "like they've got spina fucking bifida".

Alan Carr, rightly comfortable making a joke about his own minority

community, went on not only to get a dubious laugh out of people with bi-polar, but also appeared not to know the difference between it and schizophrenia.

Russell Howard's entire routine centred on an episode when his brother had "an epileptic fit". It's not that epilepsy can't be funny. It's that real comedy derives from direct experience, not from someone else's misinformed or stereotyping perspective.

Shappi Khorsandi, another performer on the bill, can be funny about Iranian culture and women because she's a woman from that culture. Next time, maybe Amnesty should book some disabled comics.

### Telegraph's blind panic

Just a hint of a flurry of worry in the dovecots as the Daily Telegraph reports: "There is mounting anecdotal evidence that Mr [Gordon] Brown is battling a serious disability."

According to the paper, concern is growing among some aides over the sight in the PM's one good eye. Sight in the other was lost following a rugby injury in his teens. He's also talked recently about having surgery to remove a cataract. People described as "friends" are

said to be concerned over the possibility of damage to his retina were he to fall or bump into something.

Whether this is the genuine concern of a major national newspaper, or the product of negative briefing to the political other side by displaced and disgruntled No 10 staff is, without exercising cynicism, difficult to call.

### → Have your say

· write to us Disability Now, 6 Market Road, London N7 9PW · email us editor@disabilitynow.org.uk

· phone us 020 7619 7323



### Beeb on the ball

Yellow cards, it appears, for **BBC Southern Counties** footy phone-in presenters Andrew Hawes and Ian Hart, who've been suspended for using offensive language on air. Hawes told one caller to "go and lick a window" and Hart then urged any other "windowlickers" to call the show. Some disabled fans might well argue that they ought to have been given straight reds.

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### disabilityrights

### Life and death choices

**Heather Roberts** (pictured, below), who lives with dementia, has strong views on living, dying and the right to choose. She says she was shocked by Baroness Warnock's comments on death as a solution for dementia

hen I heard Baroness Warnock's views about ending the lives of people with dementia I was horrified: horrified that someone would even want to think that way.

My husband Dave and I discussed what the Baroness said at some length and we wrote a letter that was published in *Living With Dementia* magazine.

In that letter, we said that deciding when someone should be "assisted to die" is a complex business. It's this complexity that makes the Baroness's statement so dangerous.

While an individual may have the right to choose when to end his or her life, in the case of dementia, by the time the point is reached when the plug could be

66 The Baroness is clearly worried about losing her own ability to think: otherwise, why focus on dementia?



pulled, that individual may have lost the ability to make the decision for themselves.

The answer is not simply to hand the decision to someone else to make, using totally arbitrary criteria.

As an intellectual, the Baroness is clearly worried about losing her own ability to think: otherwise, why focus on dementia? After all, can't all "incurable diseases" be seen as putting a potential burden on families and the NHS? Aren't the perpetually unemployed presented as a burden on other areas of the state? Where would you stop?

Baroness Warnock refers directly to "a person who is demented". When is this? At the point of diagnosis when, in reality, a person may have many years of meaningful life ahead of them? Or is it at some other point that is left open to subjective interpretation?

While an individual may wish to die when certain of their own criteria are met, no one has a duty to die. Any suggestion that such a duty exists is crass and cruel beyond words. I believe that as a person living with dementia, I have a duty to live life to the full, to leave behind a legacy that my family can treasure, and to show that dementia does not mean the end of everything.

People with dementia have an entitlement and an equal right to treatment and care, not to be defined as people having a condition that means we're deserving of death. That's sweeping the whole issue under the carpet and saying, well, we'll just get rid of them. That's tantamount to writing us off. I'm not ready to be written off yet.

In the end, while we're people living with dementia, we're not governed by dementia. At the end of the day, we're people, and every person has the right to decide what life is right for them.

 Heather Roberts was talking to Ian Macrae

### worldview





### **Beijing:** the Paralympic legacy

China has won praise for the way it hosted the Olympics and Paralympics. Now, four disabled people who attended the Paralympics tell us whether they truly herald a new era for disability rights in China



Zara Todd is a member of Equality 2025 and a campaigns officer at the disability charity Scope

China was a country I never thought I would be able to visit. It hasn't had a great reputation for its treatment of its disabled population so I was worried about how the Chinese would handle the Paralympics. And based on what I had heard, even as little as a year ago, it was a no-go destination for a wheelchair-user. China

provided a culture shock, particularly in relation to disability. Access adjustments had been attempted, but they were a halfway house compared with British standards. Even the most athletic wheelchair-user would have struggled to conquer the gradients of their ramps. For electric wheelchair-users, many of them might as well not have existed. In most cases. disabled people had clearly not been consulted and access knowledge seemed to have been learned from a book. Many adaptations looked temporary and I wouldn't be surprised if they have already disappeared. The Chinese people and

Olympic and Paralympic volunteers were all incredibly eager to assist me to access things, but they seemed to struggle with the concept that I wanted to be as independent as possible. In addition, having seen the English language translations of what was said on the news and at the Paralympics opening ceremony, I did wonder about the understanding of disability in China. It also made me wonder what China was going to be like for disabled people after the Paralympics ended. I do not know what it is like to be a disabled person in China, but I experienced the attention which disability seems to attract: I was

photographed by strangers – often from a distance – every time I went out, which suggested disabled people have been hidden from society. The exposure to the Paralympics on television was incredibly high, and I can only hope the experience of seeing disabled people contributing to society will move China's disability rights movement forward. China has travelled a long way in a short period of time, but it is only just beginning to find its way when it comes to disability rights.

· Pictured above, left and right, Zara at Beijing's Forbidden City



#### Peter White is the **BBC's disability affairs** correspondent

It's hard not to get swept along by the tidal wave that is the Paralympics. Curmudgeon though I am, veteran of four Paralympics, and three previous visits to Beijing, I did get caught up in the excitement,

and particularly the reaction of Beijingers.

There was no doubting the enthusiasm of the crowds: the Bird's Nest (pictured below) was frequently full, with more than 90,000 people, for the athletics: and the swimming-pool, the basketball stadium, and the various forms of football, all attracted big crowds. People muttered darkly about spectators being bussed in to fill the stadiums, but that's not how it looked. My sense was that



I talked to a number of local people, through interpreters (not state appointed), who were seeing a side of disability they had not encountered before. It's hard to believe that seeing athletes hurling their wheelchairs at each other, or careering around the city without a carer in sight, won't have an impact.

Equally, the changes to the travelling environment – accessible stations, buses, taxis - is bound to make people think. The danger is that, because of the lack of takeup by a disabled population not used to using the system, it will provoke the kind of questions about cost that have been raised in western countries like the United States.

What became clear was that in Beijing, and even more so in rural areas, disability is something which still goes unseen. I sat watching the

Paralympics on television with a middle-aged woman, now living in Beijing, who had grown up in the countryside. She was fascinated as we watched wheelchair tennis. Then she said, in all seriousness: "Where I grew up, there weren't any disabled people." I was incredulous. "You mean you just didn't see them; they were kept indoors?" This genuinely seemed to be a new idea to her. "Yes, there were one or two," she conceded, "but they never went out."

Such invisibility is not simply about repression it's also about well-meant over-protection, and the idea that it's the family, not the state, which should "look after" disabled people. And before we become too culturally smuq, remember two points: there are still many people whose lives are hidden in this country; and the real answer to the coherent inclusion of disabled people is a combination of caring and self-sufficiency, of protection and independence. It will be interesting to return to China in five or ten years' time to establish what the legacy of the Paralympics really was.





Sarah Carman

The advice not to tick the "mental disorder" box on my visa application was the first indicator of the state of "equality" in China. Obvious physical impairments appear to have reached a certain level of social acceptance, which works very well with the "personal tragedy" approach that seems common in China.

However, the failure to

acknowledge psychological impairments and the use of the term "able-bodied" all but ruled out those with anything but physical impairments from any discussions about disability. Given my first impressions, I chose not to disclose to many people information on my own mental health. And, since I do not visibly stray from the bounds of what is "normal". I was not treated any differently from my counterparts.

I was in Beijing for a Young Advocates Forum run by the British Council and the China Disabled Persons' Federation. I was part of a group of



Flag day: Russell Swannack (left) and Jay Lusted from the forum at the opening ceremony

young people, disabled and non-disabled, from China and the UK. For my friends with obvious physical impairments, help always seemed available, even when not requested. The adaptations were there, but in most cases, a simple enquiry as to what, if any, help was required would have restored a lot of dignity, and made adaptations more userfriendly. I do not doubt that

hosting the Paralympics has begun the arduous journey towards equality in China. I only hope this continues in the absence of international media attention.

Infrastructure changes have improved access, but what must happen now is increased knowledge and understanding of hidden disabilities, so equality can be achieved for all disabled people in China.



Graham Bool is a freelance photographer

My experience as a photographer, former GB team member and tourist was a very pleasant one. I had been warned there would be difficulty with access, communication and attitudes toward disability. But with one or two exceptions (far less than at home), including a couple of uncooperative taxidrivers, nothing could have

been further from the truth.

One subway station had just had a fine stairlift fitted, but the engineers hadn't cut off the studs holding the rail to the wall, so the lift could not pass. A colleague found a member of staff, who reversed the "up" stairlift. Down we went, safe as houses. The next night, everything had been finished and was working. There were a couple of stations that were a little more difficult to navigate but with many willing Chinese hands and my colleagues, all was soon well.

My accommodation in a three-star hotel was closer to

a five-star back home and I was persistently asked if everything was to my liking and if I was comfortable. The lifts were plentiful and had low-level buttons and Braille. Access to the hotel was a "doddle", with a long slope rather than a ramp making life very much easier at the end of a long day. At the venues and Main Press Centre, volunteers and staff were a delight, all wanting to "assist" in one way or another. Access to the venues was simple, with all routes clearly marked; all of the buses "knelt" and their ramps were in full working order.

Almost all of the shops

and cafés/restaurants I wanted to go into had ramps or slopes – even the little places - and where it was difficult, many willing hands appeared.

In the city, I didn't see many younger disabled people, although there were many at the venues.

I found the people in Beijing friendly, welcoming and curious. I was interviewed by a number of journalists from both radio and TV who mostly wanted to ask: "Why do you work, and work so hard? In China, you would be fishing and planting flowers at your age."

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### onetowatch

### **UN set for Rude awakening**

On 3 December, Rudely Interrupted, a band of disabled musicians from Melbourne, Australia, will be the first ever indie-band to play a gig at the United Nations in New York. A tour of the USA, Canada and the UK will follow. Front man Rory Burnside tells Disability Now about his impatience, love of showing-off, and Knight Rider fantasies.

#### What's the best thing about being disabled?

I get to help people understand Asperger's. I get to spend my life telling people who I am. And, with the blindness, I get extra time to do assignments at TAFE [technical and further education college].

#### What makes you angry?

One word: delays.

#### What's the funniest thing anyone's ever said to you about your impairment?

Can you read sign language?

#### What's the most embarrassing thing anyone's ever said to you about your impairment?

There was a boy at school who used to tease me and he was blind. And there's this joke about coming to see my band: "Went to see Rudely Interrupted the other night and the lead singer was blind." "Blind" is slang for drunk in Australia

#### What's the one thing that could be invented to make your life as a disabled person better?

Talking cars, so I could drive and wouldn't have to put up with taxi delays, because quite frankly it's not on, and I'm desperate to lose my reliance on the taxi service.

#### What do you most like about being a performer?

Showing the audience exactly what I'm capable of with my musical ability.



#### And what do you not like about it?

When we strike problems during a sound check and especially instruments that are out of tune.

#### Who's your favourite disabled person ever?

There was a girl at Vision Australia who I had a crush on who was visually-impaired.

#### Do you have any special or hidden talent apart from your music?

Maths and memory. Oh, and perfect pitch.

#### If you didn't have your impairment, which other one would you like to have?

It's a question I prefer not to answer.

• To learn more about the band and to hear their music visit www.rudelyinterrupted.com

#### → Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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## Trescothiak eatest

Although he faced down hostile fast bowlers and crowds alike, it was anxiety and depression which ultimately forced Marcus Trescothick from the international arena.

But, he tells **Sunil Peck**, he has no regrets

arcus Trescothick is leaving the pitch at the Oval cricket ground to rapturous applause after scoring a century to clinch the Ashes. That's how the pinnacle of his international career played out in his dreams, anyway.

In reality, Trescothick, revered as one of the finest cricketers of his generation, retired from international cricket in March after 76 test and 123 one-day appearances. As he explains in his autobiography, Coming Back To Me, the price of pursuing his Ashes dream would have been his mental health.

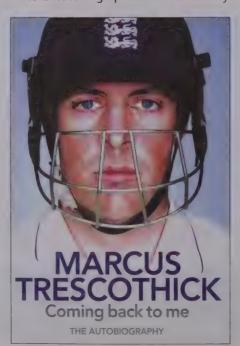
Trescothick joins Stephen Fry as a high profile figure who has gone public with his mental health problems. But although Fry has accepted his bipolar disorder as an integral aspect of his character and encouraged other people to take pride in their condition, Trescothick seems far less at ease with his anxiety and depression, and seems to see it as something to battle against.

"I know he struggled with it," Trescothick says, when I ask him if he is aware of the TV documentary Fry made about his bipolar disorder. "I'd

like to meet him and speak to him because it's always interesting talking to people who have experienced similar things."

Despite his contrasting approach to Fry's, Trescothick still says that he is not bitter that his dreams of helping England to regain the Ashes are in tatters because of his impairment.

He is notching up runs for his county



Somerset and he achieved most of what he wanted to as an England player during his six-and-a-half year international career.

Sitting opposite me in a London hotel, Trescothick says he is confident that he made the right decision to guit. "I know what it takes to play at the highest level and it takes a lot more effort than people realise. You've got to have that extra five or ten per cent that those international players have to make it happen and I don't have that any more."

His fondest England memory is of the Ashes victory in 2005 which captivated the nation, so it took some time to accept that he would not play for his country again, and particularly would not get to have another crack at the Aussies.

He tells me about one particular passage in his book. It describes how he felt when he was about to leave Australia just before the Ashes series in late 2006. England were preparing to defend their victory of the previous summer, but his depression and anxiety were forcing him to return home before the series began.



"At the time I was thinking this is the end of my career, and that was pretty painful to take," he says. He remembers sitting on a train this summer, reading this passage in his book.

"Reliving the moments when I was packing my suitcase and putting my England cap and my England shirt into my bag and reading all the memories that I was going through then was guite tough. I shed a couple of tears. It made me sad, but it also made me smile. To know how passionate I was about it at the time, but how much I've let it go since then. I don't carry that same burden around in my mind, thinking I can't believe I'm not playing for England any more."

His departure from Australia came just a few months after he had returned home early from a tour to India. While there, his depression and feelings of anxiety overwhelmed him when he saw children begging in the street. At that point, he was too scared of what the public reaction might be to disclose his mental health problems. So instead,

### At the time I was thinking this is the end of my career, and that was pretty painful to take

journalists and cricket fans came up with a series of false rumours. Had Trescothick lost his appetite for the game? Was his wife cheating on him? Did she have post-natal depression following the birth of their daughter?

While the rumours continued to circulate, he often faced abuse from opposition crowds while playing for Somerset. "They have their laugh and joke and they think it's funny," he says. "I just ignore it. Make a laugh and a joke of it, that's always the best way. Show that it's not bothering me,



hecause it doesn't bother me."

Although he says he was able to deal with such incidents, he did feel uncomfortable about the circulating rumours until he decided that the only way to end the intense scrutiny was to be honest about his condition. And he says that the moment he did so, he felt better. "There were so many bad things flying around and people making up things left right and centre, that I said the only way that this is going to get better for me is to be honest and open to people about what is going on. The minute I did, I felt so much better, purely because I had nothing to hide, nothing to be scared of."

Trescothick's batting fell away towards the end of the domestic season. But his prolific form for Somerset this year had prompted England's new captain, Kevin Pietersen, to ask if he might reconsider his decision to retire. But Trescothick refused and now says that he has no further aspirations to represent his country. "I'd love to have carried on and played 100 test matches, but it's not possible and I've accepted that if I was to do it again, I would be making the wrong decision."

But he says he never considered making a clean break from cricket. "It's been my life," he says.

It was the unfamiliar surroundings and being thousands of miles away from his family rather than pressure or disillusionment with the game that caused him the anguish he chronicles in his book.

"I'm going to be away for a week this week and I have no problem with that," he says, "purely because I know that I'm in Scarborough and I can get on a train and be home in three hours or something."

I wonder if he regards himself as



being disabled in any way? "It's the first time I've been asked that question," he says, seemingly surprised. "Maybe at the time I was struggling, I would have had a slight disability. But I feel like I've come through that."

I'd love to have carried on and played 100 test matches, but it's not possible and I've accepted that if I was to do it again, I would be making the wrong decision

He is unsure about the prevalence of mental illness among other highprofile cricketers. But while touring, he did witness colleagues showing signs of distress and home sickness. But excricketers have confided to him that they can relate to his experiences of mental illness.

"I'm sure that there are other people

who have had problems or are having similar problems. Whether they are on the same scale as mine, I couldn't honestly tell you."

Although Trescothick is basking in the relief of going public with his mental illness, he says there is a small part of him that misses being at the crease during England matches.

"I went to watch a game at Lords. It was the first time I've seen the team and the crowd in a big international game. 'Strange' is the only way I can describe it. It was just different, not having seen it before."

But he stresses that he knows he has made the right decision. "What people have got to understand is that for me to get back and play for England, I would need to sacrifice a lot and put myself in a position where I know that I would be uncomfortable. I'd love to have carried on playing and I have great memories of my time playing. But I don't want to keep doing it."

What he does want to keep doing is playing for Somerset, for as long as he can. He ponders a question about whether he might write more books in the future, then laughs and says that it will take him 20 years before he has enough material for another book.

He fancies trying his hand at coaching – as long as he does not have to uproot his family from Taunton. He thinks his experiences of dealing with mental illness would add a valuable dimension to his cricketing talent.

"I've been there when it's been good. I've been there when it's got far too much and I'm a lot more sympathetic to people when they're having problems. I'd like to think that I could give more on the coaching side, having experienced all aspects of what people can go through."

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### The tragedy of Naomi Hill

How should society react to Joanne Hill, who is thought to have been experiencing mental health problems at the time when she took the life of her disabled daughter, Naomi (pictured above)? Katharine Quarmby reports on the case, asks a number of prominent disabled women to comment and includes a harrowing first-person account from a woman who killed her own child when she was experiencing mental health problems

hen Joanne Hill, a mental health service-user, was found guilty of murdering her disabled daughter, four-year-old Naomi Hill, in September, it caused a slew of newspaper headlines in which Ms Hill, 32, was described as "demonic" and "crazed". Her exhusband dubbed her "evil".

A jury decided, in just over an hour, that Hill, who has been in contact with mental health services since she was 17, had been "in control" of herself when she killed her daughter by holding her head under a bath of water in November, 2007. She then dressed her daughter, put her in the back seat of her car and drove around with her for eight hours before eventually taking her to the local hospital. She was found guilty of



murder and jailed for at least 15 years.

Joanne Hill (above) had mental health problems for almost half her life even the prosecution, which argued she was sane when the killing occurred, agreed that was the case. The forensic psychiatrist called by the Crown as an expert witness said that she did not

have a disorder at the time of the attack but did admit that she "certainly" seemed to be ill in court. She came to court from a secure hospital, rather than from prison. Aideen O'Halloran, a psychiatrist from the secure hospital, Broadmoor, appeared as a witness for the defence and said that Hill was "suffering an abnormality of mind" when she killed her daughter. Hill first saw a child psychiatrist for anxiety, when she was just 17. In 2000, she tried to kill herself twice. In January, 2003, she was diagnosed with chronic anxiety and had a "hypomanic" episode just a few months later.

Hill blamed herself for her daughter's impairment, feeling responsible for her cerebral palsy. She was said to be ashamed of Naomi's condition and the fact that she had to use callipers, and

dressed her in trousers so that they wouldn't show. Hill had puerperal depression after Naomi was born (the most severe form of post-natal depression). She was treated in the community but had a relapse on Boxing Day, 2006, and left home to be looked

after by her parents. She went back to work a few months later and in June last year her doctors decided that she no longer needed to be seen by the local mental health team. In August, her case was closed, although she remained on medication. In November, it was

recorded that she was drinking and that this could increase the risk of her depression and encourage her to stop taking her medication. She killed her daughter just a few weeks later. She had previously begged her husband to have Naomi fostered or adopted.

### Comment by an ex-prisoner and service-user of the charity Wish (who wants to remain anonymous)

I spent a long time in segregation when I was in prison, for my own protection and because I was self-harming very seriously. I was sent to prison for killing my child; I was mentally unwell at the time, but this wasn't reported in the national newspapers. The prison officers are meant to censor the newspapers but they didn't, so the other prisoners found out about what I'd done and were abusive towards me. I had hot oil thrown over me and was slashed with a razor blade.

Being in segregation was mentally and physically uncomfortable. I had very little social contact, and the only person who came into the cell was the governor, who would visit once a day. Everybody else I had to talk to through the hatch, and I wasn't allowed to communicate with other prisoners in the segregation unit. I had no television and I wasn't allowed a

pen or a pencil, but I was given a newspaper to read. I had one hour's exercise each day, but other prisoners could see me from their cells and would yell abuse at me; staff didn't do anything to stop or discourage this.

I was put "in strips", which meant I had to wear a dress made of thick material that wouldn't rip. My underwear, hair bands and jewellery were taken away. I just wanted to sleep my time away, but the regime made that very difficult. The segregation unit always got their medication last in the evening, and we were woken up at 7am for breakfast and to clean our cells. Prison officers would laugh at me when I banged my head against the door in frustration; they didn't treat me like I was a human being.

This is just my story, but unfortunately, this is the kind of treatment Joanne Hill might expect to receive in prison. No one ever takes the time to find out the reasons behind the crime.



Ruth Bashall, co-chair. Metropolitan Police Service disability independent advisory group Joanna and

Naomi Hill were both disabled and both female. They lived in a world that cares little for us as women and as disabled people. Mothers are expected to "get on with it" no matter what, and still bear the overwhelming responsibility for children, often alone and unsupported, even by their partners. More children are murdered by their father seeking revenge on the mother who is no longer willing to be his property - yet this is seen as tragedy, not murder. Society exercises double standards - we think in terms of bad mothers and good mothers, not mothers who need support. Asking for help carries a stigma in itself. As a mother, Joanna Hill was left to "get on with it", with fatal results. As a disabled mother, she was horrified by her child's impairments. Naomi Hill is not the first disabled child or adult to be hated, abused or killed because of her impairment, and will not be the last, not unless we fundamentally change the way that society sees disabled people - and sees children not just as the mother's responsibility but as our collective responsibility.



Alice Maynard, chair of Scope "We are saddened and appalled by this case. Naomi's death is a tragedy.

"However, this

case raises the wider issue of how many disabled parents still don't get the support they need in bringing up children and how society continues to portray disability in a negative light, creating shame and stigma around impairment. This means that the parents of disabled children don't get the advice that they need to understand and deal positively with their child's impairment or condition.

"Tragically, in this instance, this combination of factors proved lethal."



Rachel Hurst, director of Disability Awareness in Action It is a tragedy that Joanna Hill should be so

deeply rooted in the prejudicial

attitudes that are so frequently held against disabled people and so repulsed by signs of impairment that they should be extended to her own daughter. Her own mental ill-health did not allow her maternal love to overcome that repulsion – another tragedy.

It is a tragedy that the authorities did not recognise that disabled

children whose parents do not want them should go on the at risk register.

It is justice, that the killing of this lovely child was judged to be murder and sentenced accordingly. We have had far too many similar cases of the murder of disabled family members where the sentence has been suspended.



Emma Bowler, disabled parent and writer When I read this story I thought it was incredibly sad. There's no denying that

a disabled child can bring additional stress. In this case, it appears the strain reached an intolerable level. But it's a complicated case as it's probably impossible to disentangle the mother's mental health issues from the issues around the fact that her daughter was disabled. Unfortunately, the lesser

informed public reaction is probably to ask what someone with a mental health problem was doing with a child, and that the child, being disabled, probably had a rubbish life anyway... ignorance fuelled by poor representation of mental health and disability generally in the media.



#### Katie Caryer, disability rights activist When I was a baby (with cerebral palsy) who did not sleep and who

cried 24/7, after a rare night of sleep, my mother on seeing me asleep in the cot thought for one fleeting moment, "Well, if she's dead, at least I'll get some sleep." As awful as it seems, I do understand what had driven my mother to think that. My mother's mental health is fairly robust, but she tells me that for a new mother of a disabled child, help, both emotional and practical, is virtually non-existent.

It is known Mrs Hill herself had impairments by the way of mental health problems and was drinking heavily. This will not take away the tragedy of a little girl losing her life, but I do feel Joanne Hill, like my mother and so many parents of disabled children, is the victim of a lack of support and services.

It appears she was ashamed of her daughter because she had cerebral palsy. This is not a rare thing. Even today, doctors are advocating the termination of "disabled" pregnancies. Parents are said to go through a "grieving process" on the birth of a disabled child (although luckily my mum says this is "bo...ks"). In the media, we are still inappropriately portrayed and we are still legitimate targets for high profile non-disabled comedians who wouldn't dream of making a racist joke. So it is no wonder some parents still believe their child is not as valuable or valued as a non-disabled child.

So I believe the guilty party in this case is society itself for not supporting the vulnerable and devaluing disabled people.

Group perspective from women with mental health conditions who have been in prison - with thanks to the charity, Wish

Everything takes a long time in prison and any woman with mental health needs might have to wait to be assessed and then wait several months for therapy. There can be long waiting-lists in prison, especially for women who need counselling. Some prisons provide a decent mental health service, so she may get psychology sessions or art therapy if it's available, but in other prisons there is very little.

Joanne will probably get quite a hard time in prison because her offence was against a child, so she's likely to end up in segregation for her own safety.

Some prisons don't even have a healthcare unit or an onsite psychiatric team.



Anne Novis, co-chair, Metropolitan Police Service disability independent advisory group I think the judge

was right in the sentencing - so often we do not get the judicial response to such matters, which I believe we should. This child had minor impairments, a supportive father and the murder was planned and executed in a despicable way. There was no excuse for this woman's actions. She hated her child because she was different. Ms Hill needs help but a life of high value was lost.



Zara Todd, member, Equality 2025 This unfortunate case highlights to me how much further the perception of

disability needs to come; no parent or disabled child should feel that the only way of coping is to end a life. This case suggests that families need more support in getting to grips with having a disability. The case also shows how influential society's attitude can be; the stigma surrounding disability and giving birth to a disabled child needs to change so no-one should feel ashamed.



Simone Aspis, disability rights activist It was the right decision for a deliberate attempt to take away Naomi's (a

disabled child's) life to be considered as murder and nothing other and that an appropriate sentence has been handed down. For too long, courts have shied away from giving a verdict of murder when disabled children have been deliberately killed. However, the lack of social and childcare support must have impacted upon Joanne's life and her mental health condition.

#### The Ministry of Justice said that it was unable to comment on individual prisoners





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### vourviews



### **Hooray, brave Mikey**

Regarding the comments made by Mikey Hughes (Disability Now October. Mikey: 'I'm a national hero) in which he said he had "noticed" something. If you are a wheelchairuser like myself you are looked at strangely by some people when you state that you are going for "a walk" and not "a ride". It sadly seems to encourage remarks like: "I thought you couldn't

walk!" Hopefully, as people learn to understand the concept of disability, they will eventually take on board that the words people use do not necessarily change once they become disabled. Well done to Mikey for having the courage to face the world from the Bia Brother House.

Dorothy Hilton, Brigg, South Humberside

### Doc who turned me down was a novice

I was disgusted to read of the lady considered fit for work because she wore a standard heel ladies' shoe (Disability Now October, Guest Column). Her bone condition was also dismissed. I had similar problems with a Department

for Work and Pensions doctor. The DWP admitted the doctor had come direct from medical school. I reported the doctor and complained that she was denying people the correct benefit. I succeeded with my appeal.

Martin Lightfoot, Peterborough

### **BBC** leads the way. despite its flaws

With reference to your story on BBC political correspondent Gary O'Donoghue (Disability Now October. Media Watch). I have worked extensively for the BBC and have ME/chronic fatique syndrome. When I was interviewed for a job at BBC Radio Cumbria, after being discriminated against in commercial radio. I declared my condition on the application form. They put me up in a hotel the previous night so I would be refreshed for the interview, and didn't ask once about my disability. I told them about it myself at interview and although I didn't get the job, I was offered a casual contract. I was allowed to work fiveto-six hour shifts, drive pool cars and report like any other journalist. When I was too ill to drive, another reporter would take over.

The BBC has specialist disability staff who play a crucial role in assisting disabled staff. The BBC's disability affairs correspondent Peter White, for example, has an assistant to help him operate complex radio and TV machinery. Peter is a broadcaster with

amazing talent and the broadcasting fabric of the nation would be much the poorer without his skill and flair as a presenter.

When I was interviewed at the BBC World Service as a trainee, I was again put up in a hotel the night before, had my train fare paid and was told they were "highly impressed". The last words on the interview panel's notes were: "Enter intake". This didn't happen and illustrates that the BBC isn't perfect, but does it deserve the scathing headlines occasioned by Gary O'Donoghue's poor treatment by one deputy editor? There is bad practice in the BBC, like anywhere else, but mostly it is an example to other employers. Ian Birch, by email

### **Better provision** might lower incarceration rate

Anne Owers, chief inspector of prisons, says "there is no doubt...there are disabled prisoners who are failed by the system" (Disability Now October, News View). My first reaction was that prison is punishment, so why should disabled convicts get preferential

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treatment? This overlooked the fact that disability takes many shapes and forms, from deafness through to wheelchair-users. Inevitably, some convicts with mental health issues should not be in prison and the idea of wheelchair-users who cannot get their wheelchairs into their cells is horrifying. Anne Owers thinks we need better provision outside prison. Maybe that would prevent many being jailed in the first place.

**Spencer Arnott, Holmer** Green, Buckinghamshire

#### **Quote policy drives** me to distraction

I read with interest the article on car insurance for disabled drivers by Helen Smith (Disability Now October, Road Test). May I suggest she try to get a quote for a wheelchair accessible vehicle? She'd be lucky to get a quote at all, even by phone, as most such vehicles are van derivatives and vans are not categorised. The question I get asked is what the logbook says. Mine says I drive a panel van, even though it is a Renault Trafic, adapted from new. The usual response is that they do not insure vans. Is it not time the motor insurance companies created a wheelchair accessible category? Tony Wyer, by email

## **New format still splits readers**

I would like to add my name to the list of folk unable to physically turn the pages because of the way Disability Now is bound.

When the new format was published, we were invited to comment on it. I got my PA to fill in the form, and said that I didn't think much consideration had been given to the people that it was for. Yet I was surprised only to read positive opinions. I had no problems turning the pages in the old format. But for anybody who has difficulty using their hands or who uses a headpointer or other gadget (as I do), trying to turn the pages now is like fighting with a paperback book.

Please look at a better binding or go back to no binding at all. I feel frustrated when I have to call for help with every page (when I can read a daily newspaper without any problems at all). Please change the binding.

Linda Sargant, by email

Last month, someone wrote in to say that they did not like the new format of Disability Now. I would like to say that my daughter and I find the new format much better. My daughter has congenital physical disabilities and I

have rheumatoid arthritis. We both read things on our laps and the size is easier to handle. Also. the paper is thicker, making it easier to turn the pages. I suppose, as with all magazines and books, it depends on how and where you are reading them as to whether it suits you. Then add in the wide range of disabilities of vour readers and it is impossible to cater for every type of need. Diane Burfoot, by email

#### **EDITOR'S NOTE**

The overwhelming majority of respondents to our relaunch liked our new style and format and we reflected this in our coverage of it. In subsequent months we've run a number of letters from people who find the magazine difficult to handle. While we're anxious to make Disability Now as accessible as possible, bespoke solutions are sadly beyond us.

#### Government has no idea how we scrimp

I've read all the articles about the increase we are facing in our fuel bills and I don't know how my wife and I will manage this winter. My fuel bill (electricity and gas) is now £1,436 for the next year. I am disabled and have severe osteo-arthritis in most of my joints, and in particular my spinal column. I have also had two major

operations on my spine and now have virtually no feeling in these extremites and little circulation. I also have angina and other health problems. I must keep warm, which means savings in some other area. But where? I already have a very tight budget for food, etc. My wife is also disabled, and has peripheral neuritis. This means she has bad circulation in her legs and feet, and in her arms

and hands. She, like me, feels the cold dreadfully, and suffers terrible pain if the temperature is allowed to drop. We live off my pension (which is not full. as I did not have full stamps) with a top-up from pension credit to bring us up to a sum which the government says we should be able to live off. What a laugh. I would like to see them live off this amount. Les Harrison, by email

# andyrickell



## Opting out is not an option

The government has a good track record on disability rights, says Andy Rickell. But to show its commitment to equality, it must sign up fully to the new UN convention

he former minister for disabled people, Anne McGuire (who was replaced last month), hoped the UK government would ratify the UN Convention on the Rights of Persons with Disabilities (UNCRPD) by December.

This should be applauded as a further step towards disabled people's human rights here and internationally, not least because the UK government played such a positive role in drafting the convention.

The current government has made the most commitment, in words and deeds, of any UK government so far in respect of disabled people's rights. Every disabled person should be lobbying their politicians of all colours so that all future governments are even more committed.

So given the current government's public commitment, it perplexed many campaigners, including myself, that the government was proposing to ratify the convention (that is, agree to abide by it), but only on certain conditions, technically

called reservations

Some of the reasons for this detailed consideration are to be applauded. Traditionally, UK governments take their responsibilities under UN conventions very seriously, so they read the small print, recognise where there are differences between UN conventions and current UK laws and government policy, and think hard about what they will do about the differences. This is good.

However, earlier this year, the government said that it was thinking about not signing up fully to a long list of issues in the UNCRPD. This list included issues it has not signed up to in any previous UN treaties, such as those that would have removed the UK's right to make its own immigration policy, but also issues in the new convention that relate to current UK disability policy - for instance, the rights to choose where you live, to go to your local mainstream school, to make decisions for yourself, to avoid compulsory medical treatment, and to be

employed in the military.

All these rights are crucial aspects of achieving equality, and there should be no wriggling out of them by any government which says it is committed to disabled people's equality.

The government is correct in recognising that current UK disability policy denies disabled people equality. The fact that the government's Life Chances report proposes equality being achieved by 2025 is an honest recognition that we have some way to go. But that is no reason to be backward in signing up to the full convention.

The UNCRPD is deliberately worded to allow countries to work progressively towards equality. Not to sign up fully implies that there is no absolute commitment to full equality.

Over the past few months, campaigners and disabled expert advisers have worked with civil

servants to address their concerns, to encourage a more positive sign-up by the government to the full convention.

The biggest sticking point is the right in the UNCRPD to attend your local mainstream school with support. This is fascinating, because disablism fundamentally arises from non-disabled people's ignorance of disabled people, for which inclusive education is the fundamental solution. Why is the government sticking on this? Because the politicians think there are votes at stake. Even the disabled children's charities agree with the disability rights campaigners. Writing immediately to Jack Straw or Ed Balls, the ministers responsible, would be a good idea.

Why expose future generations of disabled people to the disablism we suffered?

 Andy Rickell is a disability rights campaigner

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#### QUESTIONS AND ANSWERS



I am moving to Cyprus and am at my wits' end trying to find out what paperwork I need to continue receiving disability benefits abroad. I have received the higher rate of the care and mobility components of disability living allowance (DLA) since 1998, and incapacity

benefit (IB) since 1992. Michelle Shaw, via email



**Gary Martin:** Following a European Court of Justice ruling,

it is possible for some claimants to receive DLA care component and carer's allowance when they leave the UK to live permanently in another European

Economic Area member state. As you receive longterm IB, it appears you will be able to "export" DLA care to Cyprus. Unfortunately, you won't be able to receive the mobility component as you became entitled to it after 1992. Also, if you or a partner get a job in Cyprus, you would normally lose your

entitlement to exported

benefits. You should tell the DLA unit at Blackpool your circumstances are about to change, so they can reexamine your claim. It is also possible to export long-term IB. You should tell the office paying you IB and they will make a decision or send you the relevant form. Your local Citizens Advice Bureau can offer further advice.

I live with my son in a council bungalow. He is 18 and a wheelchair-user. My own condition is deteriorating and I have recently been given a powered chair. But our home is barely big enough for one wheelchair, never mind two! It has been adapted but the rooms are far too small. My son has to sleep with his bedroom door open, with his wheelchair in the doorway. When we moved in five years ago, I was told if I refused it I

#### EXPERT

Answering questions on Relationships is Simon Parritt, a counselling psychologist who has studied psychosexual therapy. Simon was the only disabled director of the former Association to Aid the Sexual and Personal Relationships of People with a Disability (SPOD). We have two Legal experts on our panel. Eleanor Williams is an employment lawyer specialising in discrimination at Darwin Gray solicitors. Disabled herself. Eleanor lectures

widely and holds a number of advisory positions. Douglas Joy is the senior solicitor at the Disability Law Service and is blind. He started working in community care and mental health law in 2002. Other **Benefits and Debt** 

questions are answered by Gary Martin, who is welfare benefits supervisor at Walthamstow Citizens Advice Bureau. Our Equipment guru is John Mandrak, who is blind and has worked for nearly 25 years as a disability

would go to the bottom of the housing list. We have been at the top of the priority move list for two years, but a large enough property is apparently unlikely. We are both getting desperate. I manage on crutches, but really need to start using my chair. Mrs P Taylor, by email



Kate Sheehan: You both have very significant needs, which

need to be assessed separately. There also needs to be an assessment of your combined housing need. Both your care managers should arrange a meeting with housing. They should stress the risk to your longterm health, and that your son's dignity is being compromised. Housing should look beyond its traditional sources, for instance at part-ownership, working with a housing association to build a property specific to your needs, negotiating with a

neighbouring council for a suitable property, or adapting level-access properties next to each other. The other option is your son moving into independent living nearby.

I am a severely disabled person and my life has mostly been spent on income support and DLA. My husband receives carer's allowance. About seven years ago, due to very illhealth, we got into a lot of debt. After advice from a Citizens Advice Bureau (CAB), a debt management company took us on and lowered our payments to £141 a month. But over half my DLA goes on the debt plan, which will last eight years. Is this my best option, and is it right for my DLA to be counted? Name and address supplied



**Gary Martin: It** is time to reassess your disposable

income and look for alternative options. The law is changing soon so there might be some new options. I would return to the CAB for a full assessment by a debt adviser. Some of the options are: IVA - a legally-binding agreement to pay part of your debts over a set period, often five years. You must have enough disposable income and/or assets to cover an insolvency practitioner's costs and leave some money for creditors. This would mean using your DLA, and even then your spare income might not be sufficient. Bankruptcy - this court order declares that you cannot pay your debts and protects you from enforcement action by your creditors. At the end of your bankruptcy (usually a year) vour debts will be

discharged and you can make a fresh start. Your DLA will not normally be taken, although they will consider your "reasonable domestic needs" and if your household income exceeds that, you may have to pay a small sum into the bankruptcy for up to three years. Debt Relief Order this gives people with debts of less than £15,000, assets of less than £300 and surplus income of less than £50 per month, relief from paying debts, which are discharged after one year. The scheme should go live in April. You probably have too much surplus income for this, but this may change after a re-assessment by a debt adviser. It is highly likely that one of these options will be better than your current arrangement.

#### → If you have a question for our panel

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journalist and consultant. He is an advisor on the Disabled Living Foundation's helpline. Answering questions on Travel is Andy Wright. who is disabled and is managing director of Accessible Travel, a

specialist tour operator providing holidays for people with mobility impairments. Our Finance expert is David Clarke, who is blind, has spent 14 years in banking and has worked for three leading financial service providers. He is now a senior partner with Clydesdale Bank. Kate Sheehan answers your questions on Property. She is an independent occupational therapist with 20 years' experience and a passionate interest in housing. Motoring

questions are dealt with by **Ed Passant**, chief executive of the Forum of Mobility Centres, the umbrella body for 17 independent organisations which provide driver and passenger assessment for disabled people.

## backchat

#### **Trevor's betting slip**

There was almost a surprising political defection by the Equality and Human Rights Commission's (EHRC) chair Trevor Phillips at the Liberal Democrats party conference.

Phillips - whose organisation's first year was described in these pages last month as chaotic, unimpressive and weak - had received another ear-bashing from a disability activist.

Phillips ended up betting the Liberal Democrat **Disability Association** 

member a bottle of his choice that he couldn't find a more accessible venue than the hotel hosting the EHRC's fringe event.

When the Lib Dem man came up trumps, he said he'd rather Phillips – once described as "a New Labour man to his bootstraps" signed up for a year's membership of the association.

In the event, EHRC rules prevented Trev joining a political organisation, so his new pal had to settle for the bottle, or a donation to his favourite charity.

#### DWP's brief encounter

Good to know that the Department for Worthless Promises, sorry, the Department for Work and Pensions (DWP), is well briefed on its new minister for disabled people. Jonathan Shaw.

When one of Backchat's colleagues rang the DWP press office for some information on the new man, he was told they had had to Google Mr Shaw to find out anything about him.

Backchat is delighted that they've found such a high-

profile operator to take up the cudgels on behalf of disabled people in the corridors of Whitehall.

#### Scoping for talent in N7

Meanwhile, reported sightings of a permatanned creature from the world of showbusiness prowling the streets near Scope's head offices in exotic north London.

Her purpose quickly became clear when she approached a colleague of short stature and asked if she would like to be an extra in the next Harry Potter film.



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## guestcolumn



# Shaking things

Disabled activists turned the traditional charity collecting box idea on its head with a week of events. Bill Albert, their chief executive, describes how they did it

ou want to give me money?" said the young woman, fumbling in her purse for a coin to put in our bucket. "Isn't that the wrong way around? Shouldn't I be giving you money?"

Of course, in the world we live in, it is the wrong way around. We are objects of tin-shaking charity, aren't we? Disabled people don't give away money to passersby. But, over the week of 22 September, that's exactly what we did in a series of market towns across Norfolk.

The events were the centrepiece of the latest annual week of action organised by the Norfolk Coalition of Disabled People, and were focused this year on the British government's refusal to ratify the UN Convention on the Rights of Persons with Disabilities without reservations.

We took the issue onto the streets in support of the nationwide efforts being lead by the UN Convention Campaign Coalition, a group of 27 disability organisations lobbying for full ratification.

On market day, disabled people from some of our 45 member groups in Norfolk set up a pitch, armed with the usual bucket. This time, though, instead of asking for money, we reached into

the bucket and offered people 20p towards the cost of a stamp to send a postcard that we supplied to their MPs, urging them to support a parliamentary motion on the convention.

These anti-collections gave us the chance not only to talk to people about human rights and their importance in the everyday lives of disabled people, but also challenged people's assumptions about disability. It was an object lesson for the well-worn

slogan, "Rights not Charity".

The responses to our action were endlessly fascinating. For example, most local councils were fine when we approached them for permission to set up in their market, but one said they didn't want us to give away money as it might offend people! For most of us in the movement, it is more than offensive to see charities sticking disabled people on the streets with collecting tins.

Most people's reaction to being confronted by moneygiving crips was favourable, even from those who tried at first to offer us money. They were amused at our tactics and overwhelmingly supportive of our aims.

Of course, some gave us a wide birth or pretended not to see us. One woman told us sternly that she'd been conned by people like us before and wasn't going to let it happen again! Perhaps she thought we were merchant bankers in disquise! A few angry people even told us that disabled people had too many rights. If only...

 Pictured, clockwise from top left, Mark Harrison, Peter DeOude, Bill Albert and Margaret Cossey

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# upclose&personal

He 'ranted and bitched' about his condition to his Big Brother housemates. But, Darnell Swallow tells Kelly Mullan, he still feels he's made a difference

arnell Swallow attended a Big Brother audition to support a friend, but stories of jail time in the USA, and the claim that he'd never seen BB. meant producers decided they wanted him for the show instead.

On his audition tape. Darnell said he wanted to represent people with albinism, but his attitude to his condition is complex. "People don't get that being albino is hard as hell," he says. "I was always bitching and ranting in the house because it's hard to convey."

Albinism affects skin pigmentation and eyesight. Darnell is black and partiallysighted, but people assume he is white and, as the BB producers supposed. non-disabled.

"Housemates understood Mikey being 100 per cent blind, but not me being partiallysighted." Darnell's tendency to "bitch" about his condition was compared with fellow contestant Mikey's apparent acceptance of his impairment.

Darnell says: "Me and Mikey got on well. We're both rebels, but I'm not easygoing. I'm rougher round the edges. I'm still dealing with a lot of things. I want different things that disability is a hindrance to."

An aspiring hip hop and R'n'B artist, Darnell says he is worried that featuring in Disability Now will damage his image. He says: "Music rivals say, 'Who does this guy think he is coming out here all fly and flashy when

he's disabled?' The industry is ruthless. Especially in hiphop and R'n'B; it's about being the best and walking with a swagger.

"It's a hindrance to be the whitest guy in the room. Entertainment's all about bright lights; I can't really see in those lights. Going into the house, I did a lot of walking back and forward. I just couldn't see where my ass was going.

"Before I go on stage I have to sit down and think how can I style this out? Everything has to be seamless. I can't be Mr Cool if I'm stumbling in."

Darnel says he found the hypocrisy of BB contestants jarring: "People say, 'Albinism's no big deal. I didn't even notice.' And I'm like, 'What? Get off my dick! Of course you noticed.' It's a lie. In this society you notice if you have a pimple, or if someone has crossed eyes, or a uni-brow.

"Housemates say, 'Your



skin is so beautiful,' and, in the same breath, say, 'My skin is too white. I need a fake tan.'

"Mikey was on the couch on his own a lot but everybody said he was their favourite housemate. The kinky stuff he said and did, no-one else would've got away with. It's a double standard. People wouldn't listen to what he said; they'd just say, 'That's amazing,' because that's what you're meant to say to the quy with the disability."

Despite his experience in the BB house. Darnell still

fears that declaring he is disabled means missing opportunities in his career. But it also depends on how the question is phrased. "If a form asks, 'Do you have a disability?' I'll say, 'Yes.' If it asks, 'Do you consider yourself to have a disability?' I'll say, 'No.'"

BB put the question the second way: Darnell answered "no". A week before the show started, he ticked the partially-sighted box on a medical form.

"They said: 'What the hell! Why didn't you say anything?' But I'm glad

they didn't find out, as they might have thought, 'We already have our disabled quy."

People say, 'Albinism's no big deal. I didn't even notice.' And I'm like, 'What? Of course you noticed.' It's a lie

On leaving the house, Darnell was shocked to read of people with albinism being killed for body parts in Tanzania. "It ruined my

day. I was speechless. It sucks that the article made us out to be a race of people. We're not a clan. It made me feel like less of a person. Looking at my girlfriend and thinking how could she want to be with me. I feel like a burden sometimes. Whoever is walking down the street with me is going to be stared at. Luckily, for now people are like: 'It's Darnell from BB.' So it has changed; at least for the next month I can ride out the BB thing."

Asked what he thinks of





disability hate crime in this country, he says: "It makes me feel more imperfect, and different and insecure. At first you think: 'It's them, it's them.' But then you start to think: 'Is it me? Is something wrong with me?"

And as for his plans for building on his BB success. he says: "I hope people with albinism don't get upset about this, but I don't want to join organisations. It would make me feel more down, so I distance myself. If I'm going to be different, which is what I am. I'd

rather be different for something that I choose."

Darnell releases his debut single on 17 November and hopes to find acclamation in music rather than as a BB star or an ambassador for albinism.

But he's happy that his visibility has made some difference to perceptions of albinism:

"I heard about an albino boy who was like me: scared, pessimistic, reserved. Now people are asking him if he's me, girls fancy him. He's the cool guy in the class now."





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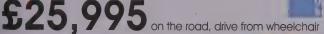
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Britain's Missing Top Model winner Kelly Knox has moved seamlessly from credit controller to catwalk model. But, she tells Cathy Reay, she's not going to fall for the celebrity lifestyle

ess than a year ago, Kelly Knox was a credit controller for a furniture company in Enfield. Today, she's a full-time model.

"I'm still the same person," Kelly insists, raising her voice so she's audible above the hubbub of her surroundings. "I just have a different job."

Just another day in the life: while talking to Disability Now, Kelly is also prepping for an appearance on the BBC show Ready, Steady, Cook.

Kelly, who was born without a lower left arm, has had hardly a moment to herself since shooting to fame as the winner of the BBC3 series Britain's Missing Top Model (BMTM) this summer.

"The day after the show ended, I went straight back to my old job," she says. "But I was sitting at my desk thinking, 'What the hell am I doing here?' It wasn't for me anymore, I

The day after the show ended, I went straight back to my old job, but I was sitting at my desk thinking, 'What the hell am I doing here?'

wanted different things."

Having been a keen follower of fashion trends throughout her adolescence, Kelly was elated when she won the BMTM competition. It meant that she got to model for a shoot with world-renowned photographer Rankin and, perhaps more importantly, leave her day job for a more glamourous lifestyle. She's now signed up with the model agency Take 2 Models.

"I've been to a lot of castings since the show ended," she says. "I've done a few things; just recently I modelled on the catwalk as part of

London Fashion Week."

Despite being thrust into the limelight so suddenly, Kelly says that she's never felt nervous: "When I go to castings and see able-bodied girls auditioning for the same job, I don't feel at all inferior. I've always felt just like everyone else.

"The 'modelling world' is the same as everyday life – you go up there, do your thing and see what happens."

It's this natural confidence that Kelly believes led to her success both in the TV series and the real world. "I thought that everyone [with an impairment] was the same as me, that they got on with it and didn't care what people thought.

"I was never bullied at school, I had lots of friends and was in the popular



groups, but some of the other girls on BMTM weren't as lucky. I think it's nice that there was someone there with a positive outlook."

The sheer volume of messages that Kelly receives, through her social networking pages on sites like

Facebook and MySpace, is evidence of how likeable she is both on and off-screen.

"I have had so many people messaging me: parents of children who are born the same way, saying I'm such an inspiration, that they are so glad they've got someone like me in the spotlight.

"One lady who had a daughter starting school told me she was really worried until she saw the show and realised that it doesn't matter if you're a little bit different."

Although she never thought herself disabled before the programme ("I didn't see a difference between me and anyone else"), Kelly says she's happy to be. considered a disabled role model for other people. "When I get messages



like the ones I've had, it makes me realise why I took part in the show in the first place."

She maintains that her favourite places to shop are River Island and Topshop, though the designer pieces she wears on set are obviously a great perk: "It's always nice to have something designer to mix and match with high street brands."

As for the celebrity lifestyle, you'll probably never find this girl at a premiere or glitzy launch: "I don't feel as though I'm part of that world at all.

I thought that everyone was the same as me, that they got on with it and didn't care what people thought >>>



I prefer hanging out with my friends, doing normal stuff!" she says.

Kelly believes that, after the success of BMTM, it is vital to continue raising awareness of disabled models.

"Because what we are doing

[putting disabled people on the catwalk] is a totally new thing. You don't know how big it is going to be," she says.

"This is all just a foot in the door for us. Who knows how it will end up."

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# localknowledge

## Virtually as good as a holiday



When Claire Wade found she couldn't leave her bedroom because of ME, she set up a voluntary organisation to bring holidays to other disabled people in the same situation. Now, she says, she is experiencing the world from her own bed

ravelling has always been my biggest ambition; but being bedbound with severe ME has made this impossible.

When I was 18, I was devastated to discover that some of my family were going on holiday without me; but I decided that if I couldn't go on holiday with them I'd do the next best

thing and bring a holiday to me. Greece was somewhere I'd always wanted to visit so my mum put photos up around my room, we ate Greek food and we even used a foot spa and pretended it was the sea.

People ask if it upset me only being able to take a virtual holiday but, in truth, I was already sad and angry and the holiday gave me

something to focus on. It was a lifeline that got me through a week that could have been full of tears but instead was full of fun.

It was this experience that inspired me to set up Holidays From Home\*. I felt that if I'd benefited so much from a holiday like this, others would too.

We provide free virtual holidays to anyone for whom leaving their bed or home is difficult or impossible or who is unable to travel due to disability or illness. The virtual holidays describe everything as if you're really experiencing it – from getting on the plane to visiting all the tourist attractions. The guides include photographs, recipes and recommended books and films, so you can bring the country's culture into vour everyday life. We have two destinations so far: Australia and New York.

Membership of Holidays From Home is free and allows online access to all our holidays via our website.

We are also running a

pilot study in Norfolk\*\*, supplying free holidays in either a book or audio CD format, funded by the Lottery's Awards for All. This is running alongside a study at the Norfolk and Norwich Hospital.

I write the holidays myself and because I'm too ill to travel, the research is done via the internet but I learn so much that I feel like I've actually been to the destinations. I find it really interesting and fun to write the holidays and I hope that people feel the same when they take them.

Holidays from Home is still in its early stages but the future is very exciting and we are working on increasing our range of holidays. I know it's going to take time, but if I reach for the world I might just get it.

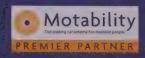
- \* www.holidaysfromhome.
- \*\* If you live in Norfolk and would like to take part in the pilot, contact Claire at contact@holidaysfrom home.co.uk

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ossibly on account of my Nordic ancestry, Iceland has intriqued me for some time, so on discovering that the specialist holiday company Traveleyes was organising a week's trip to this increasingly-popular destination, I had no hesitation in booking a place.

Traveleyes is the brainchild of Amar Latif, winner of last year's inaugural Stelios Disabled Entrepreneur Award, and offers customised holidays to blind, partially-sighted and sighted holidav-makers.

For the week-long trip, our group (12 visually-impaired and 12 sighted) were based in the Icelandic capital, Reykjavik.

Before we met at Heathrow Airport, Traveleyes had provided us with a detailed itinerary and the chance to reserve places on a number of optional tours, in addition to the sightseeing included in the package. They also arranged optional insurance and provided information about Iceland's climate, currency and culture. Equally useful was the list of fellow holidaymakers, who included travellers from Paris and LA. The information was sent out in a Word document, and is also available as an audio CD or in large print.

In line with the Traveleyes ethos, every day each visually-impaired person (VIP) teams up with a different sighted companion, which guarantees that you spend time with a good number of your fellow travellers.

Among the highlights of the week were two tours, which allowed us to enjoy Iceland's amazing geysers, spectacular waterfalls and rugged scenery.

#### Did you know?

It is believed that the first people to inhabit Iceland were Irish monks in the eighth century.

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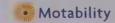
You can relax in comfort from your wheelchair. The Sportage Outback boasts rear access, alloy wheels, body coloured bumpers, a leather steering wheel and much more.

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The Golden Circle tour is said to be a "must" for any visitor to Iceland. It features a visit to Thingvellir National Park, where the world's first parliament was founded in 930, and also includes Gullfoss (the "Golden Waterfall", pictured, previous page), the Geysir hot spring (above), the Kerid extinct volcano, and the ancient Skalholt church.

The optional South Shore tour also made the most of Iceland's spectacular and rugged scenery, taking in glaciers, black sands and the opportunity to stand behind the Seljalandsfoss waterfall.

During a tour of Reykjavik we were introduced to local sculptors whose work we could appreciate by touch, and visited the house where Presidents Reagan and Gorbachev met in the mid-1980s, for what proved to be the beginning of the end of the Cold War.

The Saga Museum was another highlight, and it was great not merely listening to a pre-recorded audio-

#### Did you know?

There is no railway in Iceland.

description but also to feel the life-size figures from the country's medieval sagas. Iceland is steeped in folklore and our guide entertained us with many a gruesome tale of fearsome trolls, Viking battles and Norse gods.

One of our trips took us to where the legendary Hidden People are supposed to live. Hidden People is the collective term for Iceland's elves, trolls, fairies and other mystical creatures.

Other optional tours included a riding session on one of the many Icelandic ponies, and an invigorating walk in the dramatic countryside. Unfortunately, a whale-watching and fishing trip had to be cancelled due to some extremely rough seas.

Although comfortable and the provider of a good buffet breakfast, our hotel, Hotel Vik, was a 45-minute walk from the centre of Reykjavik, but we did find a couple of decent bistros with some surprisingly good prices within a ten-minute walk.

Some of our party found a typically Icelandic restaurant and were pleased with their fish meal - even though it worked out at about £35 a head. Things are pretty pricey in Iceland, although not as much as I had initially feared, and unlike some Scandinavian countries, it wasn't a question of having a second bottle to get over the price of the first. One traditional dish, often available at lunchtime on our trips, was a tasty and good value lamb soup (there are twice as many sheep in Iceland as people).

As for the locals, they were friendly and helpful, with excellent English. We benefited from the free bus travel enjoyed by visually-impaired passengers, and we also valued the concessionary rates at a number of sightseeing attractions, such as the Settlement Museum, which tells the story of a Viking building that was discovered in



Water treat: the geothermal seawaters of the Blue Lagoon

#### livingnow

2001 and dates from about 930AD.

I am not sure whether Iceland would win any health and safety prizes because on a number of occasions we were faced with some terrifyingly sheer drops, with very basic protection, such as those encountered by people intrepid enough to walk behind one of the splendid waterfalls.

I really enjoyed exploring Reykjavik and its brightly-painted, corrugated iron houses, its churches and the Parliament building (now of course coping with Iceland's financial turmoil).

The incredible geological phenomena with which Iceland is associated were

#### Did you know?

Iceland was the first country in the world to have a female president.



Green and pleasant land: the Thingvellir National Park

awe-inspiring, and for me the highlight was indulging in a morning's leisurely bathing at the Blue Lagoon, the popular attraction where quests can bathe and relax in geothermal seawater, and enjoy a sauna or even a steam bath carved into a lava cave. It was luxurious to step into the delightfully warm water and relax in the open air. The Blue Lagoon's skincare products also make excellent souvenirs.

Icelandic Airlines looked after us very well, and on the return flight the cabin supervisor even took the trouble of introducing herself to each of us.

Owing to airport congestion, we had to hover over Heathrow for almost an hour, but it was a chance to reflect on a highly enjoyable week.

#### Information:

For more information about Traveleyes, visit www.traveleyes.co.uk email info@traveleyes.co.uk or tel: 08448 040221. The cost for this trip was £599 per person for a sighted traveller and £899 for a visuallyimpaired person. The next trip to Iceland will be in August 2009, although prices may change.





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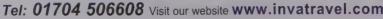
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# Velvet underground

London's new underground trains boast more space, improved features and better access. Cathy Reay visited a mock-up to see how accessible they really are

'S-Stock', the fleet of trains set to replace those on several London underground lines, claim to be the most accessible of their kind.

Myself and my colleague Jamie had the chance to check out some of their access features at a session organised by London Underground for organisations of and for disabled people.

The first improvement I noticed was the colourcoding of the train's exterior; a white strip around the red doors ensures that they stand out. Similarly, the colours are well contrasted inside, making shapes like grab poles more visible.

As the doors open, a

yellow tread-bridge fills the gap between platform and door, removing the horrific possibility of trapping a limb and making life much easier for wheelchair-users.

But the best feature has to be the generous amount of space. Clearly-marked areas enable up to four wheelchairs to travel at any time, while there is also room reserved for pushchairs and other bulky items. The fold-up seats in these areas even have a slow-retract mechanism to prevent fingers getting caught.

For the first time. passengers can put their belongings under their seats, freeing up space in the aisles. And the carriages are no longer separated by doors. Instead, people can

walk through to different areas of the train and stand in the extra space.

There have been some improvements for those with hearing impairments. too. Helpful display information panels (similar to those on overground journeys) show messages and destinations. Lights by the doors flash to indicate when they are opening and closing and, if the alarm system is triggered, lights and flashing messages will raise passenger awareness.

Following the message, passengers who need help must wait by the alarm for the driver to respond through the radio system.

But speech is not central to the culture of many deaf people, of course, and

many of them cannot use speech or choose not to. My deaf colleague Jamie also suggested that this could be very distressing to those with hearing impairments, who would not be aware that the driver was trying to speak to them, unless this possibility was clearly outlined in writing near the alarm.

Other than this, the new underground trains look and feel much more safe, comfortable and, most importantly, accessible. Oh, and I almost forgot to mention one of the best features air conditioning!

#### **INFORMATION**

Hammersmith and City

## roadtest

# A taxing problem

Older people still cannot claim disability living allowance if they become disabled after the age of 65. And this has serious repurcussions for the car tax they

have to pay, says Helen Smith

n 2007, Gordon Brown promised he would deliver "no discrimination" on the basis of race, gender, disability, sexuality, age or faith. Yet age discrimination in the benefits system is still rife.

People who become disabled after the age of 65 do not qualify for disability living allowance (DLA), so cannot get a car on the Motability scheme. Although people who become disabled after the age of 65 can qualify for attendance allowance (AA), this benefit can only be used to help with care.

For many years, the charities Help the Aged and the disabled motorists' charity Mobilise have campaigned for all disabled people, regardless of age, to qualify for the mobility component of DLA but to no avail.

Douglas Campbell, chairman of Mobilise, says: "Not paying DLA to people who become disabled after the age of 65 flies in the face of the UK government's own pledge

to end age discrimination."

However, a Department for Work and Pensions spokeswoman told me: "It is normal for benefit schemes to contain different provisions for people at different stages of their lives. DLA was designed to help those people who have the considerable disadvantage of becoming severely disabled relatively early in life so have had less opportunity to earn or save."

As well as a gateway to the Motability scheme, higher rate DLA also enables recipients to be exempt from road tax/vehicle excise duty (VED). Therefore, older disabled people who do not qualify for this benefit have to pay road tax.

Earlier this year, the government announced that it will be reforming its road tax fees to try and persuade people to buy less polluting vehicles. However, the government has not

taken into consideration the fact that disabled people often have no choice other than to drive a larger (and therefore a more polluting) vehicle. For many disabled people, therefore, this new measure will mean paying more tax.

Val and David Wilson wrote to Disability Now, saying: "We believe the proposed increase in road tax for larger cars when needed for the transport of disabled persons and their mobility aids to be discriminatory. We also feel that it is an iniquitous rule that DLA...can only be claimed before age 65. Why?

This is discriminating against OAPs who are disabled."

This is a sentiment echoed by many older people. John Mitchell, a Mobilise member, wrote to me, saving:

"Because I became disabled after the age of 65, I am not eligible for the Motability

> scheme. My current means of transport is a Jeep. Should the new road tax proposals come into force without concessions for people in my position, I shall be forced to declare my car off-road."

> Plans to increase road tax have not just outraged disabled people, but also many other motorists. Because the rises apply to cars already

on the road, people feel they are being penalised for decisions they made in the past. Due to the huge public backlash, there is a strong possibility that the government will reconsider its plans. If they don't, many older disabled people who already have no help with the cost of their mobility will have to bear yet another cost in order to remain independently mobile.

· Helen Smith is director of policy and campaigns for the disabled motorists' charity Mobilise, and is a member of the Disabled **Persons Transport Advisory Committee** 



## **Space:** the final frontier

Ford's veteran Galaxy has had an effective makeover, says Paul Carter

s old campaigners from the MPV market go, the Ford Galaxy is up there with the best of them. Around in various guises since its launch back in the mid-1990s, it is one of the long-standing MPVs and alongside rivals such as the Renault Espace, is still going strong.

The Galaxy has had a bit of a makeover in its latest incarnation and, as a result, it's as close to a looker as you're likely to find in an MPV, with the front looking more like a small car, and the back considerably more rounded than earlier models.

The interior is well designed, and all of the necessary controls are

accessibly laid out, while everything has a very solid feel to it.

Inside the car, Ford has managed to maximise the benefits of an MPV by making full use of the available space.

The rear seats fold away in various combinations and can also be removed. making it extremely customisable to suit

individual access needs.

However, if all of the seats are left in and upright, then it leaves very little space in the boot for any equipment or luggage, so family trips or holidays without a roof-rack may involve travelling rather light.

Of the many MPVs we've tested, one of the Galaxy's most stand-out features is

the fact that it drives less like a people-carrier and more like a family car.

This combined with its high driving position, low cabin noise and responsive steering make for a pleasant, if not remarkable ride.

As you may expect from a vehicle of its size, the acceleration is far from breathtaking, but in reality it doesn't need to be, and it has more than enough pull at higher revs to be able to handle motorway journeys comfortably.

With MPVs becoming less fashionable in a competitive marketplace, the Galaxy has shown that there is still life in the bigger cars yet.

However, it is considerably more expensive than Ford's other players in the field, the C-Max and the S-Max.

Whether you decide it is worth the extra cost will depend squarely on how much of a premium you place on space.

The Ford Galaxy is 1.8 to 2.2, mainly with 1.8 manual diesel is available at an advance payment of £2,750, white the top-of-the-range Ghia 2.2 diesel manual is available for an advance of E4,800



## **DOTTOW** By Paul Carter



# Canada's golden double

Wheelchair racer Shelly Woods had to make do with a double second place as she finished behind Canadian Diane Roy in the both the Tyne Tunnel 2k International (TT2K), and the Great North Run.

In the TT2K, Woods could do little to match the downhill speed of Roy, who finished in 5:19.7, almost 45 seconds ahead of her rival.

Billed as the world's fastest wheelchair race, The TT2K (above) begins with a 100m sprint to the entrance of the tunnel, and is then followed by a steep downhill run, where racers can reach speeds of almost 50mph.

The second part of the race is a 1km climb to the finish line.

Roy reached the downhill section first, and her pace opened up a gap that Woods was unable to make up on the homeward climb.

"I never touch my brakes and just go fast - 62kph, I think," said Roy. "It was fun, but the climb was very tough. I could hardly lift my arm to salute as I crossed the finish line."

Woods conceded that her downhill section let her down.

"I am always a bit slower down the hill," she said. "My strength is my climbing and I did make up a lot of ground, passing Francesca [Porcellato] about halfway up, but Diane just got too far ahead on the downhill." In the men's race,



Canadian Josh Cassidy came home first in 4:24.2, ahead of Germany's Ralph Brunner in 4:38.4.

Cassidy said: "I knew if I got a good start and could hit a higher downhill speed [than last year], I could strike back at heavier athletes on the uphill. I did it and I can say I won one of the toughest races of my life."

Great Britain's Mickey Bushell, who finished sixth, said: "It's pretty scary doing those kinds of speeds in



your race chair. You have to be totally focused. But the uphill is the killer. I have never felt pain in my arms like it, but that is what makes this race so popular. That and the unique venue."

Three days later, in the Great North Run, Shelly Woods narrowly missed defending her title in a dramatic finale to the women's race.

Woods, from Blackpool, twice a winner of the halfmarathon event, in 2005 and 2007, was again beaten by Diane Roy, this time on the line in a thrilling sprint finish.

The two racers had tracked each other in cat-and-mouse fashion for almost the entire 13-mile distance, with neither prepared to make a break early on.

It was Woods who finally made the move and looked to have done enough to hold on, but Roy came back hard at the double-Paralympic medallist to snatch a narrow victory on the line in a time of 51 minutes and 18 seconds.

Francesca Porcellato of Italy was third.

"We were neck and neck for most of the race, and I knew it would come down to a sprint," said Woods. "She was just the better woman on the day."

There was to be no heartbreak this time for Roy, who initially won gold in the T54 5,000m at the Paralympics before seeing the result overturned after a dramatic crash, and having to settle for silver in the re-run.

Woods will now turn her attention to the New York Marathon on 2 November. where she will be hoping to go one better than last year, where she finished in second place behind Edith Hunkeler of Switzerland.

The Great North Run marked a double-double success for Canada, which also claimed victory in the men's wheelchair race (above, right).

Josh Cassidy had a much easier time of things, finishing with almost a minute to spare over his nearest competitors in a race missing many of the event's big hitters such as Kurt Fearnley and Ernst van Dyk.

Cassidy clocked up a time of 44:10, ahead of 2006 runner-up Ralph Brunner, who finished in 45:03.

It meant that the results for the top two in both the men's and women's races in the Great North Run matched those in the TT2K.

## artsreview

## Attitude is the cure for access ills

Long time access activist, campaigner and chief executive of Attitude is Everything, Suzanne Bull, on why the music industry can't dis integration

s a fully paid-up member of the ticket buving public. I felt strongly that I didn't see enough disabled and Deaf people around me at gigs, so I took a cut in hours and wages to work on Attitude is Everything.

We work to improve Deaf and disabled people's access to live music by working in partnership with audiences, artists and the music industry to implement a charter of best practice across the UK.

We concentrate on the music industry because when we looked into complaints we found that museums, galleries and theatres were accessible to meet the requirements of public funding, but the music industry genuinely didn't understand their obligations under the **Disability Discrimination** Act (DDA).

I won't name and shame: we're here to help. If a venue gets bad feedback, 99 per cent of the time they're really embarrassed. They say: "Oh my God! I didn't think. This is



Reading material: Suzanne (left) on the Attitude stand at this year's Reading Festival

#### I felt strongly that I didn't see enough disabled and Deaf people around me at gigs

awful. I'm ashamed. Can you help me?"

The DDA has improved things. Expectations are higher. People know more about access. Venues are more willing now to talk and discuss access. But best practice goes far beyond the DDA. It's only a starting point and many of the venues on our charter go further.

It's all about attitude: venues can do all the things they're supposed to and say "there you go", but if they're not embracing it in their minds it won't work. It's more than just physical access: attitudes have to change.

We have a big team of mystery shoppers: Deaf and disabled volunteers who go to gigs, clubs and festivals throughout the country. They tell us what access and staff attitudes are like. It's all music, not just popular Reading bands. We have people doing opera and classical, and we have some old guys doing jazz stuff for us.

Now we're getting really good feedback. It sounds like things are changing,

especially festival access, but it's easier as the sites are temporary.

The older generation pushed for change and forced through the social model of disability. Now young people want a higher level of access and if things aren't good enough they'll shout about it. It's not enough to just provide a viewing platform. They'll say, "That platform isn't in the right place," or, "I can't read this information, it's not accessible to me." Access campaigning is going into those areas now, looking at things like lighting for people with visual impairments.

What I really want is to see more disabled artists. People now expect to see disabled people on stage and DJ-ing. I discovered the Mystery Jets when I handed Blaine a flyer on a viewing platform at a Radiohead gig. He said, "I'm in a really cool band. Can I give you a demo?" We were the first people to put on them and Heavy Load as well. Now I want to discover more talent."

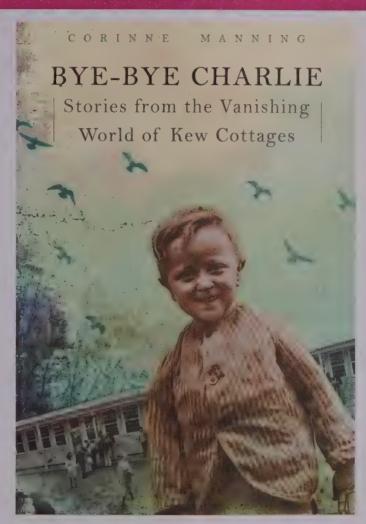
- www.attitudeis everything.org.uk
- · · Suzanne Bull was talking to Kelly Mullan

#### BOOKS

#### **Bye-Bye Charlie: Stories** from the Vanishing **World of Kew Cottages**

Opened in 1887, Kew Cottages was a large-scale institution for people with learning difficulties in the Australian state of Victoria. This book and DVD offer a fascinating insight into the world of institutional living, charting the home's 121year history and the events that led to its eventual closure, told through the first-hand stories of the people who lived there. It combines oral testimony from a range of people, including residents, families, staff, policy-makers and visitors, with documentary evidence. A graphic picture of Kew's Dickensian living conditions is painted, with persistent overcrowding, shared toilet facilities and inhumane treatment. Inadequate funding and government and public apathy resulted in the residents having to endure lives of hardship and neglect. This book will certainly carry echoes for disabled people anywhere in the world who spent time in residential institutions and anyone who still thinks that places like these have a place in the 21st century would be well-advised to pick up a copy.

While a lot of the



testimony is very strong and very direct, where the book maybe falls down is in its aim to present an unbiased oral history, where all interviewees are respectfully acknowledged and their testimony treated as equal. Although people who have long been silenced or forgotten are turned into active participants of their own history-making, their recollections are put alongside those of the

people who facilitated their oppression. Moreover, the author occasionally slips up and uses value-laden terms which undermine their claim of neutrality. For example, they talk about parents getting the "tragic news" that their child is disabled, children "suffering from

permanent disability" and the "burden of caring for a child with disabilities".

While it's admirable that Corinne Manning has given her contributors very direct voices, it's the neutrality of her own tone which just sometimes works against and even waters down some of the things they have to say for themselves.

That said, the book laudably makes the effort to be accessible to people with learning difficulties by including a DVD containing photos and audio recordings of the various interviews with the research participants.

Overall, I would recommend Bye-Bye Charlie to anyone interested in learning about the horrors of residential institutions. But overall, I think the author's voice should have been more directly on the side of her disabled contributors. As it stands, just don't be fooled into thinking you're reading an unbiased account.

#### **Laurence Clark**

· Bye-Bye Charlie by Corinne Manning; ISBN: 9781921410109; UNSW Press: 264 pages paperback + DVD; AUD\$39.95

#### → Up-to-the-minute listings

For all the very latest arts and culture listings visit www.disabilitynow.org.uk/culture



Harry
DOB: 07/01/2003



Are you an approved adoptive family? Have you ever considered sharing your home with another child? Could you be an adopter?

We are looking for a family for **Harry** who can help him reach his full potential.

Could you be that family?

Harry is a cheerful little boy who loves exploring his world and is enthusiastic about new experiences. He loves football and swimming, enjoys music and has an excellent sense of rhythm. He can feed himself, dress and undress himself, and is clean and dry. He can follow instructions and has an excellent memory. His carers describe him as a loving, friendly and very rewarding child to care for.

Sadly Harry's birth parents were unable to care for him and he was neglected at the time when he should have been developing language skills. As a consequence, Harry has been diagnosed with speech dyspraxia and is always likely to have problems communicating. His speech is developing slowly and he can now put 4/5 words together and will initiate conversation. He goes to a special needs school where he is progressing very well. He has speech therapy in school and he has a statement of educational needs.

Harry has siblings who have already been adopted and it is expected that adopters for Harry will enable him to continue to see his siblings. It is also expected that adopters will write a letter each year to Harry's birth parents to enable them to hear about Harry's progress.

We are looking for an adoptive family for Harry who can accept uncertainty about his future development. The family will need patience and determination and will take pleasure from very small steps forward.

If you are interested in hearing more about Harry, please contact Hilary Sparling, Medway Adoption Team, 01634 335675.

## webwatch

## **Shopping sites have much to learn**



Who needs to brave the winter winds when you can shop from the comfort of your computer, says **Cathy Reav**. But, as she discovers, some of the best sites are still no-go zones for some users



Not so bright: colours on the Allsaints site are too dark

Ask any of my friends what my favourite hobby is and they'll respond, possibly a little too quickly for my liking: shopping.

Visually my temptation is fashion, aurally I love popular music and when it comes to taste buds, there are no barriers.

But with the winter months closing in and Oxford Street preparing to turn itself into London's Tinseltown, it's hard to muster the energy to leave the sofa. Luckily, with "estores" cropping up all over the web, I don't have

to move an inch.

But how accessible are they? I asked Julie Howell. director of accessibility at Fortune Cookie, the web design experts, to give me some pointers.

One fashion site I go to is www.allsaints.co.uk, though their online selection is limited and their pages have dark colours and scripts that make visiting them hard for anyone with visual impairments, says Julie.

www.asos.com also has scripting problems and is confusing to navigate, she says. It's a shame these smaller retailers don't seem to consider making their websites accessible for all customers.

When it comes to music. most people will tell you that www.play.com or www.amazon.com are the best for reliable delivery, price and range.

That's all well and good but if you're after something a little more "boutique", I love

#### www.sisterrav.co.uk.

It's brilliant for collectables like that rare Joy Division 12" or the Lou Reed album you can't remember the title of.

On the downside, its "independent" nature makes it far less accessible than the bigger brand sites.

And so to food. Though a bit pricier than Tesco, www.sainsburys.co.uk is undoubtedly the biggest and best online catalogue; it even promises to deliver within a one-hour time slot, perfect for just before or after work.

As I have a physical impairment, it helps that, on request, its delivery staff will dump my order on the kitchen table for me. But Sainsbury's relies on that pesky scripting software, too, limiting its potential audience vet again.

If you're feeling naughty (or maybe just frustrated, after all that browsing). www.thorntons.co.uk delivers cross-country too - for the few of us that can read its site, that is.

Next month, we will be examining obstacles faced by disabled people when doing their shopping.

If you've had problems dealing with supermarket staff or in the shopping aisles themselves or navigating a retailer's website, email cathy.reay @disabilitynow.org.uk with your name, and contact number (if you have one), describing your experience.

#### → Have your say

- · write to us Disability Now, 6 Market Road, London N7 9PW
- · email us editor@disabilitynow.org.uk
- · phone us 020 7619 7323

## worklife



## Supporting people

Librarian Rebecca Marshall's professional skills have been recognised by her peers. But she couldn't have done it without the support of her employers

ntreatable", "nothing we can do", "just going to get worse". Those were the words the hospital used when I was diagnosed with arthritis. I was almost 18 years old and about to leave for university. I had felt like the world was at my fingertips.

My mother told me that it wasn't "the end". She was right. I haven't always been able to do certain things, but that's only made me more determined.

I left university with a 2:1

in English and history. I loved researching and finding out information and got a job as a library assistant. I did a distance learning masters in information science and two years in, got the job of professional librarian at Lipson Community College in Plymouth.

I work at a strategic middle-management level; contrary to popular belief, I don't actually run the library! I teach students how to access and retrieve information so they can use it in their studies.

Two years into my job, I also took on the role of head of careers. I love the feeling that sending students off to university gives you, the reward of it. I also teach A-level critical thinking.

I love the diversity of my role and that Lipson has allowed me to expand into other areas. As employers, they have been nothing but understanding. I'm a firm believer that if you show a company you are worthy, you'll get the support you need.

Earlier this year, I was nominated for the School Library Association School -Librarian of the Year award by the vice-principal. Assessors came to meet me and the staff and students at Lipson and they whittled the nominees down to six - the "honour list". The six of us attended an awards ceremony (pictured) in London and went to the House of Commons to meet MPs and education ministers.

At the end of the day, my knees and hips hurt so badly and I'm always incredibly tired. I go to bed at 8pm every night and it feels like I have no life out of school. I sometimes resent that my career takes

l'm a firm believer that if you show a company you are worthy, you'll get the support you need 🥍

from my time as a mother and wife and I hate that I have to take painkillers every day and go into hospital twice a year to keep me going.

I wonder how long I'll physically be able to keep working at this level. But this would happen with any iob and I know that if I was sat at home I wouldn't be happy. This is what I want and I know it is right for me.

· Rebecca Marshall was talking to Cathy Reay

#### **REBECCA MARSHALL: CAREER PATH**

- 1994-1997 2:1 in English and history from Plymouth University
- 1998 out of work for nine months due to major operation on left knee
- 1999 assistant at Plymouth Central Library, and began masters in information and library studies
- 2001 professional librarian at Lipson
- 2003 head of careers at Lipson
- 2006 began teaching critical thinking at Lipson, in addition to other roles
- 2008 on the honour list for SLA School Librarian of the Year



# When Scope and DIAL UK merged in August we knew we were going to be busy...

We've had over 50,000 enquiries in our first month. We're not surprised. After all, disabled people and their families are fighting for equality every day: whether that's trying to get access to civil, social and political rights; to get a job; to be able to communicate; in fact, just to be treated equally.

Our expanded information and advice network offers the best of local knowledge and national disability expertise. Every day we are supporting people to be in control of their lives.

We knew we were going to be busy, but we will never be too busy to take your call...

**Scope Response** 

www.scope.org.uk/response Freephone: 0808 800 33 33 Email: response@scope.org.uk

**Text** SCOPE followed by your message to 80039

**DIAL UK** 

www.dialuk.info

**Tel:** 01302 310 123

Email: dialuk@scope.org.uk

Scope is a registered charity



dialuk
serving the disability advice network

Time to get equal

scepe

About cerebral palsy.

For disabled people achieving equality.

Information, advice and support when you most need it



## Sussex Health Care



Sussex Health Care is an award winning group of care homes that were founded in 1985.

Sussex Health Care now operate 15 care homes, predominantly in the West Sussex area, providing nearly 550 beds, incorporating specialist care provision as well as care for older people.

### In 2008 the group are developing 2 new purpose built facilities

Beechcroft Care Centre, West Hoathly Road, East Grinstead and

Horncastle Care Centre, Plawhatch Lane, Sharpthorne, East Grinstead

Beechcroft Care Centre, which opened in May 2008, is in East Grinstead and caters for ten young people with physical disabilities and learning difficulties. Person-centered planning is at the forefront of our philosophy with the service users' needs and wishes at the centre of our service.



This care home provides specialist nursing care and is equipped with the latest technology aids to provide a safe, comfortable, homely environment for our service users. **Beechcroft Care**Centre is a specalist care home with ten places for people with learning and/or physical disabilities.

It offers superb purpose-built facilities with track hoisting throughout. Each single room is provided with en suite facilities. A swimming pool and spa pool are available to all service users along with sensory and physiotherapy rooms.



### Horncastle Care Centre, Plawhatch Lane, Sharpthorne, East Grinstead

This service is due to open in August 2008. It will provide a purpose built residential service with 24 hour nursing support for people with acquired brain injury and neurological conditions.

### Sussex Health Care operates the following award winning care homes:

BEECHCROFT CARE CENTRE (Physically Disabled & Learning Difficulties) East Grinstead 01342 300499
BEECH LODGE (Physically Disabled & Learning Difficulties) Broadbridge Heath, Horsham 01403 791725
CLEMSFOLD HOUSE (EMI) Broadbridge Heath, Horsham 01403 790312

MSFOLD HOUSE (EMI) Broadbridge Heath, Horsham 01403 790312 FOREST LODGE (EMI) Nutley, Nr Uckfield 01825 712514

HORNCASTLE HOUSE (Adult Care) Sharpthorne 01342 810219

KINGSMEAD CARE CENTRE (Adult Care & Physically Disabled) Horsham 01403 265335

KINGSMEAD LODGE (Physically Disabled & Learning Difficulties) Horsham 01403 211790

LONGFIELD MANOR (Adult Care) Billingshurst 01403 786832

NORFOLK LODGE (Learning Difficulties) Horsham 01403 218879

ORCHARD LODGE (Physically Disabled & Learning Difficulties) Warnham 01403 242278
RAPKYNS CARE HOME (Adult Care) Broadbridge Heath, Horsham 01403 265096

RAPKYNS CARE CENTRE (Physically Disabled & Learning Difficulties), Broadbridge Heath, Horsham 01403 276756

UPPER MEAD (Adult Care & Medical Conditions) Henfield 01273 492870

WHITE LODGE (Learning Difficulties) Purley, Croydon 020 8763 2586

WISTERIA LODGE (Physically Disabled & Learning Difficulties) Nutley, Nr. Uckfield 01825 714080

### For further information

Please contact Corrine Wallace, Head of Operational Services and Future Development

Tel: 01403 217338 • Fax: 01403 210424 email: corrine.wallace@sussexhealthcare.org





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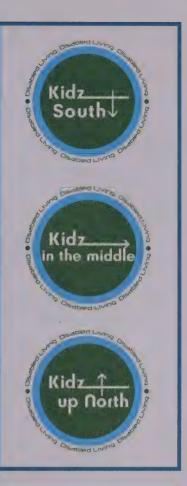
- Kidz Up North Thursday 20th November 2008 Reebok Stadium, Bolton. New and coming soon by popular demand:
- Kidz in the Middle Thursday 12th March 2009 Ricoh Arena, Coventry.
- Kidz South Thursday 18th June 2009 Rivermead Leisure Complex, Reading.

For more information or **FREE** visitors entry tickets contact the organisers: Disabled Living, Redbank House, 4 St Chad's Street, Cheetham, Manchester M8 8QA.

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Email: info@kidzupnorth.co.uk • Web: www.disabledliving.co.uk www.kidzupnorth.co.uk

> President: Gerry Yeung OBE Registered Charity Number 224742



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### CARS/VANS/CARAVANS

#### **VOLKSWAGEN TRANSPORTER**

2.4, off road grey, diesel, auto, air con, central locking, e/mirrors and windows, CD player. Lowered floor and lowering suspension with Torspring ramp. Wheelchair points behind driver. Carries 5 including wheelchair. Registered August 07, 6k miles, asking £17,750. Willing to show locally. Tel: 01400 272201 (Grantham, Lincs) or email: p.manderfield@btinternet.com

#### **CHAIRMAN CITROEN**

**BERLINGO** 1.6, registered June 03 (03 plate), silver, pas, e/front windows, e/mirrors, c/locking and air con. Full Gowrings Wheelchair Conversion incl rear fold-down ramp, carries 5 including wheelchair. 32k miles, MOT expires June 09, one owner from new, fsh. £6,200 ono. Tel: 01225 833229 (Bath).

### **CITROEN BERLINGO 1.9,**

diesel, gold, pas, e/windows and e/mirrors, air con, central locking, registered September 1999 (V reg). With Brotherwood Wheelchair Conversion incl lowered floor with rear ramp and anti-slip locks. Only one owner from new, £2,795 ono. Tel: 01495 311886 (Ebbw Vale) or mobile: 07840 096681.

**FORD FOCUS ZETEC 1.6.03** plate, black, e/windows and e/mirrors, pas, CD player, air con, c/locking, leather heated seats, parking sensors. With Constables Carchair Conversion incl wheelchair in front passenger position, with 2 rear seats. Only 17k miles, MOT and tax expires May 09, only 2 owners from new, with fsh, asking £8,500 ono. Tel: 01754 880768 (Lincs) or

mobile: 07521 027532.

**HYUNDAI ATOS, FITTED** with

keypad and ball for one handed driving. Manufactured by Lodgesons, fitted by approved installer. This device conforms to all regulations. Silver metallic, auto, air con, e/windows. 5 door hatch, Reg Feb 2000, 39k genuine miles. 3 owners, new MOT. £1700. Tel Richard: 01474 812323 (Gravesend, Essex).

**VW SHARAN SETDI Auto** 1896cc diesel 1998 R reg, only 50,897 miles, metallic silver with grey/blue cloth upholstery, 2 owners, auto, ic, Central locking, electric windows, air con, radio, 12 months' MOT. Adapted by Automotive Group to provide 5 seats plus wheelchair space at back of vehicle. Lower hinged tailgate full width ramp - very easy to use. 4 point wheelchair anchorage system and seat belt. Service history. Location: Slough,

Berks. £4,100 ono. Tel: 01753 529501 or 07759 258608 or email: joyceamirahmadi @yahoo.co.uk

2001 FIAT SCUDO JTD. Lowered floor, lightweight ramp, 4 point wheelchair tie down system, electric winch, A/C, ABS, CL, EW, PAS many other extras, GM Coachwork conversion, seating 4-5 and a wheelchair. Excellent and reliable van! £3,500. Contacts: neliharvey@btinternet.com or call 07960028368 (Exeter).

RENAULT KANGOO '05 (05 req) 1.6, auto, seats 5 or 3 plus chair. Allied Vehicles Autograph Conversion with lowered floor and winch to assist loading. 1 owner with history, Condition as new. 8k miles, fsh, £8,995. Tel: 01737 557756 or email: bob@ paavansales.co.uk TRADE

Cont'd see pg 76

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For disabled people achieving equality.

### **DN** Deadline

December published 22 November. Classified deadlines: Booking: 3 November. Copy: 5 November.

#### CHAIRMAN FIAT FIORINO

1.7, diesel, M reg (1994), white with Gowrings Conversion incl rear manual ramp and electric winch with 4 anchorage points. Carries 5 including wheelchair. Only 61k miles, in very good condition, full MOT until Feb 09, asking £950 for guick sell. Tel: 01986 896186 (Bungay, Suffolk) or email: sjhqw@fsmail.net

#### CHRYSLER GRAND VOYAGER

2.5 CRDLX, blue metallic, 03 reg, MOT expires April 09, e/windows and e/mirrors, pas, CD and DVD player, privacy glass, alloy wheels. Jubilee Conversion with folding rear ramp, inertia belts and anchor points. Carries 5 including wheelchair. Fsh, 2 owners from new, only 34k miles. Asking £10,850 ono. Tel: **01443** 473094 or mobile: 07768 25576.

#### **CHAIRMAN RENAULT**

KANGOO 1.2, metallic blue, 07 reg, only 1,000 miles, pas, CD player, central locking, air con. With Growrings Conversion incl 2 button operated winches, lightweight fold-down ramp and inertia belts. With full Gowrings service, second owner used vehicle only once, in immaculate condition, asking £9,500 ono. Tel: 020 8657 3027 (Croydon).

### WHEELCHAIRS/SCOOTERS

#### DAYS VIPER POWERCHAIR

with charger and push handle, jet black, covers 10 miles on one charge. With raising function, rear shelf for storage, head and foot rests. Remote – displays and operational controls, electrical adjustment for back and seat angle. Back handle to allow pushing, battery housing, antitippers. Horn key on remote, driving speed display, key for selection of electrical adjustable components. In immaculate condition, has never been used. full warranty and relevant brochure and paperwork. Bought for £4,471 last November, asking £3,250 ono. Tel: 0113 2675819.

### RECRUITMENT



The Chartered Institute of Housing is the professional body representing people working in all sectors of housing. Our mission is "To maximise the contribution that housing professionals make to the well being of communities". We have over 21,000 members in the UK, Asian Pacific and other parts of the world. With offices in Coventry, London, Cardiff, Edinburgh, Belfast and Hong Kong, the Institute is now seeking to recruit the following post based at our Coventry office:

### Positive Action For Disability Manager

Salary on appointment £30,183, rising to £35,112, subject to performance plus substantial benefits.

Ref: CIH/COV/08-11

We are seeking a specialist in employment services for disabled people to be in from the beginning of our work to increase the number of disabled housing professionals.

Working on your own initiative and calling on significant relevant experience, you will turn our vision to place 12 people per annum into 2 year traineeships into reality. You will promote the scheme to housing organisation partners and support them in providing effective placements. You will ensure that trainees get the quality services that will sustain them in programmes of study and work based learning.

To be effective in this role you will be used to working to tight deadlines and negotiating timescales and service costs with colleagues and external partners. You will be confident in leading projects and you will be driven to champion change within CIH and the housing sector.

Closing date for applications: 12 noon on 7th November 2008 Interviews will take place on 26th November 2008 at our Coventry office.

To request an application pack please telephone our 24 hour Recruitment Line on 024 76851728. e-mail: hr@cih.org Text your address details to 07887 787 465 or submit a CV with full salary details to: The Human Resources Team, The Chartered Institute of Housing, Octavia House, Westwood Way, Coventry, CV4 8JP. Relevant forms and further information about the CIH can also be downloaded from our web site at www.cih.org/jobs

Previous applicants need not apply.

#### Open to all, closed to prejudice

The Chartered Institute of Housing aims to be an Equal Opportunities Employer. We do not require applications via agencies.



### Director of Service User Involvement



Supporting people with disabilities to help themselves

### £32,238 pa pro rata (NJC Scale PO3 pt 39) 24 hours per week

The strategic aim of this new exciting post is to lead LOD into the next phase of our development to become The ULO (User-Led Organisation) for Devon. You will be working with commissioners and others to promote the social model of disability, and providers of services to ensure they are underpinned by the principles of independent living.

The successful applicant will be a positive role-model, empowering, developing and supporting disabled and Deaf people to influence policies, rights and entitlements across Devon. You will have personal experience of disability and/or be a member of the Deaf community.

Closing date: 12 noon on 13th November 2008

Interview date: 3rd December 2008

For an application pack please telephone 01392 459222, email info@livingoptions.org or download it from our website www.livingoptions.org

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power chair, black, outdoor and indoor use, 6 years old in good condition, speed up to 4 mph, 40 amp battery up to 20 miles, upgraded with swing away left hand multi speed joystick controls REM 24SC, tension adjustable back upholstery, angle adjustable footplates, padded seat, puncture proof rear tyres, Dynamic battery charger included, Service history. Cost £3,265. Location: Slough, Berks. £1.099 ono. Tel: 01753 529501 or 07759 258608 or email: joyceamirahmadi@ vahoo.co.uk

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Cont'd see pg 78

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Toyota Hiace 2.5 D-4D Diesel Manual DA57LRE, 14,200 miles, Metallic Blue. The New 2007 Face Lift Model, Registered January 2008. Well specified model with 5 seats. Rear access ramp with winch.

VW Caddy Life MPV 1.9 Diesel Manual DK57CFV, 1,714 miles Metallic Silver, Registered November 2007, 4 seats with colour coded bumpers and mirrors, climatronic air-con and rear parking sensors Torspring Ramp and winch.

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VW Cruiser MKIII 1.9 Diesel Manual YN07FKO, 4,774 miles, Metallic Silver, Registered July 2007. High spec vehicle with 6 seats and much sought after side access conversion with under floor lift

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If you're interested in changing attitudes to disability and supporting other disabled people then visit www.LCDisability.org

Image reproduced from the "Creature Discomforts" disability awareness campaign www.CreatureDiscomforts.org

Leonard Cheshire Disability charity no: 218186 (England & Wales) and no: SCO05117 (Scotland)

Leonara Cheshire Disability

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consider me as having made myself deliberately homeless if I give up my flat in Leamington Spa, but won't help until I start the job (chicken and egg scenario!). I have two powered wheelchairs, a computer desk, and live in support, hence 3 bedrooms. Please tel Sarah: 01926 831768, email: sarah@sidavies.me.uk



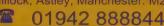
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IF YOU WERE on the YDH holiday to Paris in August 1993 or any YDH holiday in the past 20 years, I would love to hear from you by letter or telephone call. Whether you are disabled or a volunteer do contact me on 07826 299356 or write to: Joy Jones, 11 The Bristol, Gainsborough Square, Lockleaze, BRISTOL BS7 9XA.

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2003 Fiat Doblo Aspen 1.9d SX (J8339) Blue, 4 seats, 33,500 miles, Lightweight Ramp, Lowered rear floor, £5,995

2003 Renault Trafic SWB 1.9 DCI (J7582) Blue, 85,600 miles, Ricon Taillift. £7,995

2005 Chrysler Grand Voyager Auto 2.8 ltr Turbo Diesel (J8334) Met black, 4 seats, 37,000 miles, Full Width Lightweight Ramp, Lowered rear floor, £15,995

2007 Renault Master SWB 2.5 DCI Turbo Diesel (J8223) Silver, 4 seats, 14,000 miles, Full Width Lightweight Ramp. £12,750

2007 Fiat Doblo Aspen I.4 Petrol (J8281) Silver, 2,000 miles, Lowered rear floor, 3 seats, Lightweight Ramp. £9,995

2003 Renault Kangoo Auto 1.4 ltr Petrol (18229) Green, 3 seats, 25,000 miles, Lightweight Ramp, Lowered rear floor. £6,500

2004 Renault Kangoo I.2 I6 valve Petrol (J7623) Blue, 3 seats, 17,066 miles, Lightweight Ramp, Lowered rear floor. £8,395

2008 Renault Kangoo I.2 ltr Petrol (18279) Met blue, 3 seats, 1,900 miles, Lightweight Ramp, Lowered rear floor. £9,250

2008 Peugeot Expert Teepee SWB Montana MK3 HDI (J8201) Azzuro Blue, 4 seats, 1,700 miles, Lightweight Ramp, Lowered rear floor. £19,750

2004 T5 Volkswagen Caravelle SE 174 BHP manual (18343) Silver, Under floor electric wheelchair lift. £15,995

2002 Volkswagen Caravelle SWB 2.5 TDI VK02 ZKF (18330) Blue, 6 seats, 69,000 miles, Electric Wheelchair Lift. £6.995

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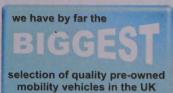
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2008(57) Renault Kangoo 1.6 Authentique auto, silver, 3 seats, 600 mls
2008(08) Renault Kangoo 1.2 Authentique, blue, 3 seats, 200 mls
2008(08) Peugeot Partner 1.4 Combi 5sp, red, 5 seats, 1,000 mls
2008(08) Peugeot Partner 1.6D Escapade 5sp, silver, 5 seats, 300 mls
FAMILY MPV wheelchair accessible up to 30 in stock including

2505(50) 1 50g061 artifol 1.4 Combi 65p, 160, 6 36dis, 1,000 illis	£11,230
2008(08) Peugeot Partner 1.6D Escapade 5sp, silver, 5 seats, 300 mls	£12,295
<b>FAMILY MPV</b> wheelchair accessible, up to 30 in stock including	
2001 (Y) Kia Sedona SX 2.5 auto, gold, 4 seats, 41,000 mls	£8,995
2002(52) SEAT Alhambra 2.0S 6sp, grey, 5seats, 30,000 mls	£11,995
2005(05) Volkswagen T5 1.9D, 5sp, green, 5 seats, 42,000	£12,995
2003(03) Mercedes Vaneo 1.6 Family 5sp, silver, 4 seats, 29,000 mls	£12,995
2005(05) Volkswagen T5 1.9D, 5sp,blue, 5 seats, 38,000 mls	£13,995
2005(05) Kia Sedona 2.9D LE 5sp, silver, 4 seats, 22,000 mls	£14,495
2004(54) Mercedes Vaneo 1.6 Trend auto, red, 4 seats, blue, 47,000 mls	£14,495
2004(54) SEAT Alhambra 2.0S 6sp, blue, 5 seats, 39,000 mls	£14,995
2006(06) Kia Sedona 2.9D LE auto, grey, 4 seats, 19,000 mls	£14,995
2004(04) Mercedes Vaneo 1.6 Family auto, red, 4 seats, 23,000 mls	£15,495
2008(57) Volkswagen Shuttle 1.9D 5sp, blue, 5 seats, 2,000 mls	£16,995
2007(07) Kia Sedona 2.9D LS auto, blue, 5 seats, 9,000 mls	£19,495
2007(56) Vauxhall Zafira 1.9D Design auto, silver, 4 seats, 9,000 mls	£19,995
2006(56) Chrysler Grand Voyager LTD XS diesel auto, 4 seats, 12,000 mls	£23,995
LARGE wheelchair accessible, up to 25 in stock including	
2004/54) 0' 0' 0' 0' 0' 0' 0' 0'	

LARG	E wheelchair accessible, up to 25 in stock including	
2001(51)	Ciroen Dispatch 1.9D 5sp, blue, 3 seats, 39,000 mls	£6,995
2001(51)	Renault Master 2.2D SL28 5sp, blue, 4 seats, 29,000 mls	£8,995
2004(54)	Citroen Dispatch 1.9D 5sp, navy, 4 seats, 49,000 mls	£8,995
2007(07)	Citroen Dispatch 1.9D 5sp, red, 4 seats, 2,000 mls	£13,995
2005(05)	Renault Master 2.5D 5sp, silver, 5 seats, 21,000 mls	£14,995
2007(07)	Renault Master 2.5D SL280 5sp, grey, 5 seats, 5,000 mls	£16,995
WHEE	LCHAIR DRIVER up to 10 in stock including	
2006(06)	Vexel Quovis Drive From auto, yellow, 3,000 mls	£6,995
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## backlash



## Scaling the north face of my toilet

The real story of the Tory conference will have to wait until I publish my memoirs, says Paul Carter. If I survive that long...

'm still alive, readers. If you were concerned that I was going to meet my bitter end at the hands of one of my ever-growing army of stalkers, then don't worry. Unless of course I actually have perished at the hands of an obsessive devotee and my employers are pressing ahead with my column as some sort of mawkish tribute. If they are then I don't condone it.

In fact it's been fairly quiet on the stalking front this month. I was accosted by a few slightly strange old men at the Tory conference, but let's face it, if there was anywhere I was likely to be accosted by slightly strange old men, it was there.

I can't reveal too much information, though, as it seems people in high places read this column these days, so any salacious political gossip I may or not have heard in lifts will have to wait for my memoirs, for which incidentally I am open to offers for the publishing rights.

My hotel, though, was the biggest drain on my frail emotional reserves.

The staff were very nice, but way, way too helpful for



my liking. Every time I came in, one of the porters would insist on walking me to my room, opening each door along the way and continually asking if he

66 Whatever time of night he was around, he'd be there at breakfast as well, like some hotel automaton 99

could carry my bag. Not so bad, you might think, until one night, when I thought I'd managed to sneak in without him noticing. Oh, no! He clocked me before I could get through the first door, and before I knew it, he was chasing me down the corridor as fast as his legs could carry him, waistcoat flapping in the breeze, purely so he could beat me to opening the second door. It felt like I was in a scene from *The Shining*.

Whatever time of night he was around, he'd be there at breakfast as well, like some hotel automaton. I made the mistake of eating in the restaurant one evening, and because it was so quiet, he'd be there hovering, ready to pounce on the off-chance that I might need some food

cutting. I ended up staring directly ahead for the best part of an hour, because if I made the slightest bit of eye contact he'd appear next to my table, ready to waft some crumbs off the table with his hair. Or something.

The toilet was fairly spectacular as well. I'd been put in what I assume was a "disabled room", which I identified by the ratio of handrails to square foot of wall space. The crowning glory, though, was the toilet. It had clearly been designed with a wheelchairuser in mind, but for a short-arse like me it made using the toilet like scaling the face of Kilimaniaro. At one point I thought I was going to have to set up camp, and get the crazy porter to bring some rope and act as a Sherpa.

It can't have been that bad, though. After all, David Davis was in the same hotel. I began to wonder if he had the same problems with his toilet, which was frankly something I never imagined myself thinking. If I want to know the answer, I suppose I'll have to buy his memoirs.



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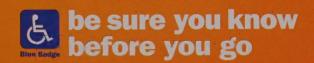
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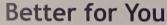
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